

JOHN-MANUEL ANDRIOTE

VICTORY DEFERRED

*how AIDS changed
gay life in AMERICA*



A note about the cover: Veiled by the American flag, the battle helmet of the Sacred Band of Thebes provides an image of the bravery and valor passed down the ages to the legendary warriors' latter-day descendants forced to confront a plague of biblical proportions. Twenty-three hundred years ago, in ancient Greece, the Sacred Band were renowned for their courage, and for decades remained undefeated until Alexander the Great and his father Philip's vast army slaughtered them at Cheronia. Even then, Philip honored the men's bravery by constructing an enormous carved lion to serve as the soldiers' mausoleum. Men were chosen for the Sacred Band because they were homosexual, and the three hundred men who comprised the group were actually one hundred fifty couples. The Sacred Band has often been referred to as an "army of lovers." Members of New York City's Gay Activists Alliance in the early 1970s spoke of the growing gay movement as an "army of lovers." The army grew to vast size and proportion in the AIDS epidemic, as many brave men and women joined the battle against the twin-headed monster of HIV and homophobia. The red AIDS ribbon binds together in hope all those wishing and working to end the global pandemic and the fear, ignorance, and prejudice that have allowed it to fester for three decades, and counting.

VICTORY DEFERRED

Praise for *Victory Deferred*

WINNER Lambda Literary Awards “Editors’ Choice”

HONORED BOOK American Library Association

FINALIST New York Publishing Triangle Randy Shilts Award

“The most important AIDS chronicle since Randy Shilts’ *And the Band Played On*.”

— *Kirkus Reviews*

“This is an impressive piece of journalism, likely to supplant Randy Shilts’s successful *And the Band Played On*. Like Shilts, Andriote has his prejudices and his favorites, but he is more balanced and less prone to assume he knows what people were feeling or thinking at critical moments.”

—Dennis Altman, *The Age* (Australia)

“Andriote has interviewed every major player in his nearly two decades of reporting as a journalist on AIDS, and it shows.”

— Jose Gabilando, *The Washington Post*

“A fine history of the epidemic, keen and thoughtful. Andriote shines with chapters on less covered but no less important subjects, including the multi-billion dollar ‘AIDS industry’ and private fundraising groups. He brings together in one place many facts and figures heretofore unsynthesized.”

— Joe R. Neel, *The Boston Sunday Globe*

“Andriote’s adroit integration of the personal and the historical results in an illustrative, analytical account of the disease and its impact on the gay civil-rights movement. His depiction of the poignant struggles, heroic responses and resultant social and political gains emanating from AIDS is a perceptive document for our time, relevant to all readers, regardless of their sexual orientation.”

— John R. Killacky, *Minneapolis Star-Tribune*

“People who want to know how a community mobilized in the face of an unprecedented crisis will want to start here.”

— Jonathan Rauch, *Los Angeles Times*

“Andriote has honored his mentors, his muses, and his community by preserving an important chapter in gay cultural history.”

— *The Washington Blade*

“Remarkable. Medical writing for the non-professional is tough, and here the blend of biomedical and sociological information is truly consummate. *Victory Deferred* is everything it has been claimed to be.”

— *Oasis Magazine*

“Andriote...offers a comprehensive survey of the many ways AIDS has transfigured gay social and political life...A well-researched and nuanced portrait of the many levels on which this grave disease has wrought both destruction and transformation.”

— *Publishers Weekly*

“Andriote combines broad strokes and telling details in this engaging history of the complicated war against both disease and bigotry. Recommended for public and academic libraries.”

— James E. Van Buskirk (San Francisco Public Library)
Library Journal (starred review)

“*Victory Deferred* is a careful and considered exploration of how gay culture has been reshaped by this disease; Andriote’s work is not only compelling and eminently readable, but a vital addition to the canon of literature on AIDS.”

— Abraham Verghese, physician and author of *My Own Country* and *The Tennis Partner*

“As *Victory Deferred* eloquently delineates, there have been heroes in the epidemic who, in the face of microbial horror, discovered character within them that exceeded anything they’d previously imagined of themselves.”

— Laurie Garrett, author of *The Coming Plague* and winner of the 1996 Pulitzer Prize in Journalism

VICTORY DEFERRED

**How AIDS Changed
Gay Life in America**

S e c o n d E d i t i o n
UPDATED AND EXPANDED
Open Access Edition

JOHN-MANUEL ANDRIOTE

John-Manuel Andriote began reporting on HIV-AIDS while he was a graduate journalism student at Northwestern University in the mid-1980s. In 2008, the Smithsonian Institution created the “John-Manuel Andriote Victory Deferred Collection” at the National Museum of American History, to make available for researchers the original audiotape interviews and other materials used to develop the book. Visit jmandriote.com.

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Adapted from the (2011) Second Edition (Updated and Expanded), with a new foreword for the open access edition.

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In memory of
Dad, Allen, Bill, and Rich

This edition is dedicated to my beloved (late) mother, Anna,
who showed me what love looks like.

As I ponder'd in silence,
Returning upon my poems, considering, lingering long,
A Phantom arose before me with distrustful aspect,
Terrible in beauty, age, and power,
The genius of poets of old lands,
As to me directing like flame its eyes,
With finger pointing to many immortal songs,
And menacing voice, *What singest thou?* it said,
Know'st thou not there is but one theme for ever-enduring bards?
And that is the theme of War, the fortune of battles,
The making of perfect soldiers.

Be it so, then I answer'd,
I too haughty Shade also sing war, and a longer and greater one than
any,
Waged in my book with varying fortune, with flight, advance and
retreat,
victory deferr'd and wavering,
(Yet methinks certain, or as good as certain, at the last,) the field the
world,
For life and death, for the Body and for the eternal Soul,
Lo, I too am come, chanting the chant of battles,
I above all promote brave soldiers.

—WALT WHITMAN

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FOREWORD TO THE OPEN ACCESS EDITION

For this October's LGBT History Month and Open Access Week, I have collaborated with a dedicated librarian at the University of Chicago Library to re-release *Victory Deferred: How AIDS Changed Gay Life in America* as an open access book. The theme of this year's LGBT History Month, "Medicine: #UnderTheScope," encourages us to celebrate and remember the contributions of gay, lesbian, bisexual, and trans people in the fields of medicine and health care. *Victory Deferred* certainly celebrates and remembers them—and so many more.

The theme of this year's Open Access Week (October 21-27), "Community Over Commercialism," perfectly captures the reason I am making *Victory Deferred* available, free and globally, via open access: because anyone interested in HIV-AIDS, LGBT history, and American history should have access to the hundreds of accounts from community leaders and pioneers I interviewed and cite in the book. Their experiences during a supremely challenging time offer insight and wisdom for many of the challenges we face today. As Jonathan Rauch put it in his *Los Angeles Times* review of *Victory Deferred*, "People who want to know how a community mobilized in the face of an unprecedented crisis will want to start here."

Start here because the HIV-AIDS epidemic is inextricably linked to LGBT history. And *Victory Deferred* uniquely documents and details how community-level organizing, fundraising, protesting, and lobbying in response to HIV-AIDS literally transformed the national LGBT equality movement. As historian John D'Emilio said in our interview for the book, "AIDS built the LGBT movement."

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In the quarter-century since *Victory Deferred* was originally published, the promise of transforming HIV from a death sentence into a chronic, manageable condition was expanded further with new ways of taking the lifesaving drugs now available to treat it. Once-daily combination tablets and long-acting injectables have made treatment as simple as it has ever been. Longer-acting implants are being studied. Meanwhile, research steams ahead to discover cures and effective vaccines thanks to new vaccine technologies that advanced during the COVID-19 pandemic. By now it is well-established that “Undetectable = Untransmittable,” meaning that a medically managed, undetectable HIV viral load renders an individual unable to transmit the virus through sex. Pre-exposure prophylaxis (PrEP) also protects uninfected people from sexual infection.

And yet, long-term HIV survivors—commonly defined as those diagnosed before the 1996 introduction of combination antiretroviral therapies—face the challenges of what research is showing to be a kind of accelerated aging. Then there are the emotional scars. They run deep in the “older” gay male community who bore the harsh brunt of the “dark years” when all our friends seemed to be sick and dying at once. Aging without the friends and lovers we expected to know all our lives, deep sorrow lurks, always, just beyond our laughter. How has it impacted our lives in the twenty-first century? I shared some of how it has impacted my life and what AIDS taught me and us about our own resilience and strength in *Stonewall Strong: Gay Men’s Heroic Fight for Resilience, Good Health, and a Strong Community*, my book I describe as a “bookend” for *Victory Deferred*.

The publication of memoirs and films about the AIDS crisis may be evidence that more of us who lived through its worst years are better able to take stock of what we lost—and what

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we gained—with some perspective that we couldn't have had while it was our present reality. I certainly sensed, when I interviewed people for the 2011 second edition of *Victory Deferred*, that they were eager to get their personal story out there while they were still alive to tell it themselves.

Despite recent challenges to the full equality and humanity of LGBT Americans, the national equality movement—spurred so powerfully forward by the community's responses to HIV-AIDS—continues to enjoy the benefit of its greatest legal achievement to date: marriage equality. The US Supreme Court's 2015 *Obergefell v. Hodges* decision found that the U.S. Constitution's fourteenth amendment guarantees same-sex couples the right to legally marry.

In fact, HIV-AIDS propelled the marriage equality movement—just as it did the broader LGBT equality movement. “AIDS was a wake-up call,” Evan Wolfson said in our interview for *Stonewall Strong*. The Harvard-trained lawyer, nicknamed “Mr. Marriage” for his singular, decades-long push for marriage equality, explained, “It woke up gay people to our vulnerability in being excluded from legal protections for our relationships. AIDS also made activists realize they needed to exchange gay people's traditional ‘leave us alone’ posture toward government for a ‘let us share and participate from within’ approach.” Wolfson said that AIDS also woke up non-gay people. “Americans got to see this very different vision of who gay people were, and that helped set the stage for changing hearts. I think AIDS played an enormous role in paving the way to change hearts and minds and understanding in the non-gay world so we could change the law *and* change our place in society.”

Five years after the triumph of the *Obergefell* decision, the United States and the entire world suffered through the fear and uncertainties of the early COVID-19 pandemic. We who

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lived through the early AIDS years drew on our resilience. We followed the recommended precautions and went about our lives without an excess of panic. Slipping on a face mask in a crowded space felt considerably less intrusive on our freedom than putting on a condom in the heat of passion. Despite another Republican president mismanaging a public health crisis, Dr. Tony Fauci proved a trustworthy medical and scientific guide through the dark COVID days—just as you will read in *Victory Deferred* he proved to be through the HIV-AIDS crisis.

October 27 will mark nineteen years since my own doctor in Washington, DC called to share what he called the “bad news” that I had tested HIV-positive. I am grateful to say I benefit from the tremendous advances in HIV medical treatment. I was HIV-negative while writing the original edition of *Victory Deferred* in the 1990s. Revisiting the accounts and stories I share in the book, filtering them through the experience of a man living with HIV himself, I’m struck by just how remarkable those stories are—the tales of courage, loyalty, and love in action on the front-lines of a great war against both hatred and a deadly plague—as told by the “soldiers” who fought the war while it was ongoing.

To those who would claim that HIV-AIDS in 2024 is no longer an important concern for gay men or the LGBTQ community and its lobbying organizations, I would simply cite the facts: The Centers for Disease Control and Prevention (CDC) report that gay and bisexual men accounted for 67 percent (25,482) of the 37,981 new HIV diagnoses in the US and six territories in 2022. Black and Latino gay men are most strongly affected, comprising about 38 percent of those diagnoses. The CDC estimates that half of Black gay men will be diagnosed with HIV in their lifetime—if nothing changes.

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I first interviewed longtime San Francisco activist Paul Boneberg in the 1990s for *Victory Deferred*. When I interviewed him again in 2015 for *Stonewall Strong*, the founding director of Mobilization Against AIDS—the first AIDS activist group anywhere—said there was only one choice for gay men in San Francisco when AIDS struck: fight or flight. “AIDS made us choose,” Boneberg said. “Most chose to stay and fight.” He added, “It is my experience that our community is heroic.”

This is precisely why I often speak of our LGBT “heroic legacy,” the stories we must hand down our generations to celebrate the brave men and women who stood up for equality, freedom, and justice when it mattered most. *Victory Deferred* details in its intimate firsthand accounts and national scope what those heroes in big cities and small towns across America endured and accomplished in the face of stigma and a deadly epidemic. And now anyone in the world will be able to read, free, in the new open access edition about what we endured and achieved in one of the most challenging periods in LGBT and American history.

John-Manuel Andriote
Atlanta, Georgia
October 2024

PREFACE FOR THE SECOND EDITION

I wrote, and have now updated and expanded, *Victory Deferred* because, despite the abundance of books written about AIDS, no one before or since its original 1999 hardcover edition has drawn as extensively from firsthand accounts to examine both the “big picture” and its finer details in considering the many ways AIDS affected the nation’s hardest hit community, gay and bisexual men.

I wanted to mark the thirtieth anniversary of the AIDS epidemic with a new edition of *Victory Deferred* because, in the years since its original publication, the book has assumed a unique role in the literature on AIDS. It has become a kind of repository of firsthand accounts from hundreds of individuals whose lives were shaped by, and who in turn shaped the world’s responses to, AIDS. In fact, the audiotapes and transcripts of the interviews I conducted for the book, as well as the other research materials I used to develop it, are now archived in the Smithsonian Institution’s “John-Manuel Andriote *Victory Deferred* Collection” at the National Museum of American History. Interviews and artifacts from the collection were featured in the museum’s 2011 exhibit marking the anniversary.

Collectively, these stories of tragedy and transformation are of both historic, and human, significance. They record for posterity the terrible price once-marginalized Americans—condemned as evil, sick, sinful, and second-class—paid in lives lost, even sacrificed, in their efforts to achieve full citizenship as a deadly epidemic raged among them and their fellow citizens couldn’t agree as to whether or not they were “equal.”

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As I write this, only one in six of the estimated thirty million people worldwide living with HIV is receiving antiretroviral treatment to manage the infection. In the US, more than nine thousand HIV-positive Americans, who have been determined to need medication and are already approved based on standard income criteria, anxiously wait for the federal and state governments to adequately fund the AIDS Drug Assistance Program. Without the life-saving medications they need, our fellow citizens face the same prospect of illness and death as everyone with HIV before the mid-nineties advent of antiretroviral therapy. With neither a cure nor a more cost-effective treatment in sight, leading scientists say it is unrealistic to expect the world's nations to pay the trillions of dollars it would cost each year to provide HIV treatment for everyone who needs it.

Today HIV prevention includes treatment for those with the virus. Studies show that lowering viral load means there is much less risk of transmission to an uninfected partner. But without a vaccine to prevent the spread of HIV, the best hope for prevention continues to be—as it has been for three decades—behavioral interventions based on providing information to support people's efforts to make healthy and informed choices. In the meantime, human nature being as it is, the plague continues.

For so many of us, AIDS has cast a dark cloud over our entire adult life. I first heard of it in 1981, shortly after the earliest cases were reported. I was twenty-three at the time, living in Boston, and only recently “out” and sexually active as a gay man. AIDS seemed far off then, in New York and San Francisco, where it affected “the clones,” the butch men in Levi's who sniffed poppers when they danced or engaged in much more

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sex than I was having. Within three years, two of my friends were already dead from AIDS and I knew of others.

As close as I was to the epidemic for so many years—as a reporter, as a member of the gay community, as the friend who brought his own electric shaver to the hospital to shave the face and uphold the dignity of my former lover as he declined into dementia and died at age thirty-four, I remained HIV-negative myself.

I never expected to mark the twenty-fifth year of AIDS, in 2006, by telling the story of my own then-recent HIV diagnosis in the *Washington Post* and on National Public Radio. Like most newly diagnosed people in this country, I had no clue I was infected because I had no symptoms. Yet by the time my doctor said, “I have bad news on the HIV test,” the virus had already damaged my immune system. If I’d not had an HIV test as part of my routine annual checkup, I probably would not have found out I was positive until I became sick with a life-threatening illness. “This is so ‘eighties,” I told my doctor.

Having lived on both sides of the viral divide, I can say with certainty: the view is very different from this side. My deepened personal perspective is another reason I wanted to revisit the history I chronicled in *Victory Deferred*. I have a far better appreciation today of what it really meant—what it said about courage and gay pride—to be one of the men who first went public about having AIDS in the early 1980s. Now I not only relish the retelling of their heroic stories as a reporter, but I am deeply grateful that men like Bobbi Campbell and Bobby Reynolds in San Francisco, and Michael Callen and Richard Berkowitz in New York City (and Richard still today), blazed such a brilliant trail for the many more of us who have walked this treacherous path.

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Victory Deferred looks at how AIDS affected gay America in almost every conceivable way: culturally, medically, politically, and socially. It traces the transformation of a disorganized collection of despised individuals into a self-affirming community and a full-fledged civil rights movement. It tells the story of a people who practiced the adage, "Charity begins at home" by developing volunteer-run service organizations, designing novel and effective prevention campaigns, raising millions of dollars for research and care, creating memorials to the stricken, and wielding the tools of political pressure to wake up national leaders who wanted nothing to do with a disease perceived as afflicting "undesirables."

My aim is to provide an "inside" look at the effects of AIDS on gay people and the gay civil rights movement—and how gay people, we, have pushed and pulled a reluctant nation (and world) into action in combating the epidemic. Reviewers have often compared and contrasted *Victory Deferred* and Randy Shilts's *And the Band Played On*. It is important to remember that Shilts chronicled only the first six years of the now-thirty-year-old plague, less than one-fifth of the period covered in *Victory Deferred*. Shilts's story unfolded amidst very real fear, ignorance, and terror, when there was no effective medical treatment for HIV infection. Shilts reported from the frontlines of the battlefield as extraordinary numbers of young men continued to get sick and die around him. He chronicled the darkest of what gay men today call the "dark years." *Victory Deferred* chronicles that terrible time, revisiting it but also putting it in perspective against the epidemic's three decades to date. As a fellow journalist, it is an honor merely to have *Victory Deferred* mentioned together with Randy Shilts's *And the Band Played On*. For my reader, it's important that you know why you must read both books.

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With few exceptions, I have intentionally “painted” from a palette of grays a picture of the people and events of the three decades since the start of the epidemic. Like life itself, few things in the AIDS years have been black or white in their moral or medical certitude, and few people have been exclusively heroic or cowardly. I expect readers will draw their own conclusions from this depiction of people, places, and moments in time. I believe, however, they will recognize that the story of gay people in the AIDS epidemic is not merely a story of the 1980s or 1990s but of human history as it is played out in all times and everywhere.

The book is a work of journalism, and represents one writer’s attempt to organize and explain a complex and multifaceted cultural, medical, political, and social phenomenon. It is not the work of a professional historian aiming to interpret people and events through a theoretical construct that purports to “make sense” of them. The book also is not a treatise on AIDS activism, fundraising, politics, prevention, psychiatry, sexuality, or any other specific topic; each of these is considered in the text because it is a facet of my overall subject of how AIDS changed gay life in America.

In telling the story—stories, really—of how AIDS changed gay life in America, I draw mainly upon the more than 200 interviews I conducted throughout the United States in the 1990s for the original 1999 edition, and the six dozen more I did in person, by telephone, and Skype for this new edition. People living with HIV, activists, caregivers, doctors, fundraisers, lawyers, parents, scientists, and volunteers speak in these pages about their experiences, the lessons they learned, and the losses they sustained. I have woven their accounts together with material gleaned from extensive research in the consumer and professional literature to tell the story of a people moved and transformed by a health catastrophe that unfolded amid a hostile—at

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times, hysterical—social and political environment. I offer assessments of why things happened as they did, and suggest how they fit into a larger scheme. I organized the book thematically because of the vastness of my subject. Its eleven parts are subdivided into chapters. Each one explores an aspect of gay America's experience in the AIDS plague. Together they move from the beginning to mid-2011, thirty years into a now-global plague everyone expected to be over by the end of the 1980s.

It is important to state that I have written a sympathetic account—but not an uncritical one. This will rankle those who insist on particular points of view, or “political correctness,” even when they contravene the facts. I do not toe anyone's line, whether talking about bathhouses and sex clubs, ACT UP, or lobbying efforts in Washington. I will irritate those who feel that any challenge to what I call a “ghetto mentality” is a homophobic assault against all gay people. I will annoy those who believe that AIDS fund raisers should be “left alone” and not held accountable because they are “doing God's work.” I will touch a nerve in addressing the tensions between AIDS organizations run by people of color and the so-called “AIDS establishment” that has included the larger and wealthier groups started primarily by white gay men and women. Some are bound not to like my assessment of the current state and shaky future of AIDS service organizations, ignoring my conclusion that the services they offer must continue to be provided, even if no longer by freestanding disease-specific agencies. Still others will argue that the national gay political groups “really are” still committed to addressing HIV, even though their programming priorities indicate otherwise.

Despite my commitment to calling spades spades by challenging the “PC,” or status quo, version of events, individual actions, or earlier interpretations, I believe that astute readers will

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take away an appreciation of what gay people have struggled against, how we have been affected by it, and why we gained in social and political stature because of the humanity and strength—and public anger—we demonstrated in responding to AIDS. If they keep an open mind, both gay and nongay readers alike will be impressed by the ability of gay people to pull together to find solutions to the multitudes of problems that AIDS brought upon us.

As a Washington journalist for more than two decades, and writing about AIDS and gay politics and culture since the early 1980s, I've had an ideal vantage point from which to observe the unfolding of the national gay civil rights movement and the nation's response to AIDS. I watched with a combination of horror and fascination as I saw AIDS devastate so many lives and as I watched so many people—including, most remarkably, those living with the disease itself—come forward and demonstrate, repeatedly, that charity and nobility are more than old-fashioned virtues. I have seen too much mortal illness and death, among too many of my friends and colleagues, at too young an age. I have also been privileged to witness truly extraordinary displays of heroism. And I now know firsthand the fear, medication side-effects, rejection, stigma and piercing awareness of my body's fragility and my soul's resilience, that come from living with HIV.

Against criticism that the current volume is incomplete because AIDS is still with us, I take shelter in Albert Camus' point that any record of a plague "could not be one of final victory." As *The Plague's* narrator, Dr. Rieux, explains, "It could be only the record of what had had to be done, and what assuredly would have to be done again in the never ending fight against terror and its relentless onslaughts, despite their personal afflictions, by all who, while unable to be saints but refusing to bow down to pestilences, strive their utmost to be healers."

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I want to extend my appreciation to all those who took the time to speak with me for the new edition of *Victory Deferred*. Something I enjoy most in the interviews is the chance they offer my interviewees to reflect on their work in a way that enables them to see its connections to the “bigger picture,” the national and even global efforts to address the HIV pandemic. I continue to be grateful to those I interviewed for the original book, as well as to all the friends and colleagues I thanked in it.

I’d particularly like to again thank Doug Mitchell, my original editor at the University of Chicago Press, for wooing me back then with long e-mails and head-swelling comparisons to far worthier chroniclers of the ancient Greek past, and for publishing the book. Thanks to the Arcus Foundation for the grant that helped to support my research for this second edition. Particular thanks to Fred Davie and Urvashi Vaid, then Arcus’s director. Hats off to the Gill Foundation, its director Tim Sweeney, and to Broadway Cares/Equity Fights AIDS, and its director Tom Viola, for the support they provided to produce and publicize the new edition of *Victory Deferred*.

I am pleased once again to thank my college advisor and mentor Delvin L. “Doc” Covey for reading and critiquing the new final section of the book. At age ninety, Doc continues to inspire me with his admonition, “Live while you are alive!” Nearly forty years behind him and since we first met, I still aspire to follow his wise and loving instruction.

Thank you also to Bob Wood for reading and accepting the portrait I painted of him in the new final section. Our interview in Seattle stands out in my mind and I am grateful for Bob’s willingness to open his heart as he did. Thank you to friends who provided hospitality during my reporting trips. Sandra Jacoby

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Klein and Don McCallum were great hosts in Los Angeles. And over several sweltering New York days in July 2010, Laura Goldstein and Randy Feuerstein (and Peewee the parrot) were as hospitable as ever. Thanks to those who have helped to keep me well in every sense as I have faced my own changed health status and all it has meant in my life. I'd like in particular to thank my doctors, Ben Stearn and Michael Barnett in Washington; Ken Abriola and Tim Quan here in Connecticut.

I rely in particular on the encouragement and support of my friends Rod Mercer, Thom Minner, and Greg Pappas. Thank you, gentlemen. My dear friend Dennis Pfaff was the first person I called after my doctor called with his "news" in 2005. I treasure our long friendship. Thank you, Dennis. And thank you for our hours of companionship to my friends here in Connecticut, especially Jimmy Hooper, Tami Patterson, Christopher Smith, and Bob Zarnetske.

More than anyone, my mother Anna Farnan Andriote, has cheered me on and sustained me with life's necessities when my own resources dried up. When I "came out" to her in 1983 about being gay, she said, "I want you to be happy." When I "came out" to her twenty-three years later about being HIV-positive, Mom told me, "Be brave, John." The challenge to live bravely is less onerous, thanks to her.

I (continue to) abide in honor, love, and loss "too deep for tears," as Wordsworth put it, for the men to whose memory I have dedicated *Victory Deferred*, each of them a powerful force in shaping the man I am and the work I do today. My father, Manuel John Andriote, urged me to question what I don't understand and to ask for help when I need it. Allen Satterfield showed me by example what a life of integrity looks like, and wrote poetry for me. My former lover Bill Bailey urged me to

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write about AIDS, and fought so valiantly to prevent others from contracting it even as it stole his own life. My friend and beloved "Sitto" Rich Rasi told me "trust your gut." Well, my gut says it still hurts like hell to live with the loss of these men I've loved.

John-Manuel Andriote
Norwich, Connecticut
September 2011

INTRODUCTION

Not long before his own death from AIDS, Randy Shilts, our best-known chronicler of the early years of the epidemic, said that the ability of gay people to forge solutions even as they coped with the horrors of AIDS remained “one of the great untold stories of the 1980s.” In fact, to tell the story of gay people in the AIDS epidemic is to describe variations on the very theme that reverberates throughout human history: the brave few struggling against a powerful enemy as the silent majority chooses ignorance over involvement because they don’t see themselves as personally at risk.

The solutions gay people forged have served as models for the nation and the world. Their common element, and most striking quality, has been the extraordinary level of volunteerism behind them, the time and commitment given because “someone has to do it.” Gay people and their supporters demonstrated the “love in action” that, as Mother Teresa saw it, truly is God. When AIDS first struck gay men, in 1981, activists quickly rallied to share information, provide services, raise money, prevent new infections, and demand assistance from a skittish federal government.

Within a month after the first cases of AIDS were reported, New York writer Larry Kramer wrote in the *New York Native*, “This is our disease and we must take care of each other and ourselves.” In early 1982, Kramer and five other well-known gay men met in Kramer’s living room to make plans for Gay Men’s Health Crisis, a volunteer-run organization that would raise money for research and offer services to gay men afflicted with what was then called “Gay-Related Immune Deficiency,” or GRID.

The same year, leaders in San Francisco’s gay Castro area formed the Kaposi’s Sarcoma Education and Research Foundation, better known as the San Francisco AIDS Foundation. Within a few years, hundreds of organizations were formed throughout the country

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and around the world, modeled to one degree or another after these two early groups. Similarly, Pat Norman's AIDS Coordinating Committee, a group of mainly gay and lesbian community leaders in San Francisco in the early eighties, provided the earliest model for the now \$2 billion-plus comprehensive AIDS services program funded by the federal Ryan White CARE Act—and for the kind of “continuum of care” that is now being touted in the US as the preferred standard for all in need of medical services.

My overarching conviction, which permeates this book, is that what the gay civil rights movement fundamentally seeks is a society in which individuals are able to love themselves as nature and nurture have combined to make them, and everyone can enjoy the freedom to love regardless of the sex of their beloved. If being gay is about love, an essentially private experience, it follows that life for gay people is an essentially private business—just as it is for heterosexuals. But because homosexual love is so feared and reviled in American society, gay life traditionally has been doubly private, the love and often the actual lives of gay men and lesbians hidden from the eyes of disapproving heterosexuals. Given the human need for connection with others, though, the “love that dare not speak its name” drew together people in similar circumstances as friends and lovers who could freely speak the name of their love.

Before AIDS forced open so many closet doors, gay life revolved mainly around circles of friends and lovers, and their interconnections with other similar circles across the country, even around the world. Despite the personal contacts, however, there was very little sense of belonging to a “national” gay community.

When hundreds of thousands of gay men and lesbian marchers filled the streets of Washington in 1979, 1987, 1993, and again in 2000, Americans—including many gay people themselves—were astonished at the size and diversity of the gay community in this country. AIDS brought the gay community as a community out of the closet.

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The story of gay America in the AIDS plague is ultimately that of men and women who cared for their own and showed the world that neither disease nor human kindness has sexual preferences. Gay people and our nongay allies banded together in sorrow and rage, boldly demanding recognition of our loves and losses, even as activists and lobbyists fought for money to conduct research into HIV, care for the sick, and prevent others from becoming infected with HIV.

Gay people in the HIV epidemic showed our heart: that it was capable of great love, that it quickened with anger and fear, and that it broke, too, from the weight of so many losses. As Virginia Apuzzo, former director of the National Gay and Lesbian Task Force, said when I interviewed her in 1995 about political issues for the book, “Talk about our institutions, the legislation, and appropriations—it’s important and I hope you do a good job on it. But if you do all of that, and don’t talk about the grief and pain, and the fact that we still fight for the right to love—if you think of anything less—you miss the whole point.”

An inescapable and discomfiting point in describing gay people in the AIDS epidemic is the fact that many gay men in the early years of the epidemic—some of them still today—ignored the dangers of AIDS because, among other things, it meant having to change their sexual behavior. Forced to be “sexual outlaws” by an oppressive American society, many homosexuals defined themselves as society defined them, by the very trait that distinguished them from heterosexuals: their sexuality. It was one thing they fully possessed, and they were damned if they’d let anyone take it away from them.

But the question ultimately became, plainly and simply, whether sex was worth dying for. In the process of answering that question, the community devised ways to help men change their behavior—while reinterpreting sexuality and redefining what it means to be gay in affirmative, life-saving terms. Perhaps the greatest of gay people’s many accomplishments in addressing AIDS has been the creation of a diverse community that nurtures its members to see themselves as distinctive for many reasons besides their sexuality alone.

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Camus tells us in *The Plague* that the essence of heroism is caring for others as “a matter of common decency.” Even as we were derided as “immoral” by religious conservatives merely for our sexual orientation, gay people were driven to the forefront of the war against AIDS by a strong sense of common decency, the will to survive, and love. The boldness that gay people gained after the 1969 Stonewall uprising meant that neither the shame of the closet nor the stigma of a fatal sexually transmitted disease would stop us from speaking out about the medical and political injustices we were experiencing. We deflected homophobic assaults as we pressed on toward the goal of surviving—and ultimately conquering—the scourge that afflicted us so cruelly and disproportionately.

As we hope, pray, and fight for ultimate victory over both the viral enemy and the oppression of antigay hatred, the struggle with AIDS itself has changed us and reshaped the way many of us think about ourselves, our health, our sexuality, our community, our nation, and our future. Gay people during the AIDS epidemic experienced in a compressed fashion—and mostly at a young age—the physical and emotional suffering that priests and poets from time immemorial have described as part of the “human condition.” The hatred and condemnation of self-appointed judges, on top of efforts to remain uninfected or to live with the physical, psychological, and social challenges of the disease itself, have made life in the era of AIDS a moral crucible, an unwelcome and severe test of our individual and collective mettle.

I hope you will read *Victory Deferred* as the remarkable story of a people who were determined to survive the biological catastrophe of AIDS and the spiritual violation of oppression. The story is set at the juncture where culture, medicine, morality, and politics intersect—as volatile, even dangerous, a battlefield as ever existed. It’s about learning to speak the language of politics and science in order to save lives. It’s about the efforts of well-intentioned but inexperienced people who founded and ran AIDS organizations that, over time, became part of a vast, multimillion-dollar industry. It’s about our successes, mistakes, the battles we won, and the terrific losses we sustained. It’s about individuals and a community’s coming of age under

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the most extraordinarily difficult circumstances and against the greatest odds. It's ultimately about people whose battle against an epidemic was propelled by their love for one another and their desire to be able to love freely.

The book also is a witness to the gay men who have lived and died in the AIDS plague, and a legacy to future generations of both gay and nongay people.

Above all, it is the story of how the members of one community—an army of lovers—were conscripted into service in a war that neither they nor any other human being ever chose to fight. We were, of supreme necessity, made extremely brave soldiers, engaged in a fight against both a faceless viral enemy and human enemies whose faces too often contorted with hatred.

Fierce as it has been, we can never forget that the struggle with AIDS is ultimately but one skirmish in the war in which every living thing is engaged, against what St. Paul called the last enemy that shall be destroyed: Death.

PART 1

THE FIELD

*Is this not a night of nights!
It's the beginning of the summer of our lives!*

LARRY KRAMER, *FAGGOTS*

Being gay in the seventies meant hot men, cool drugs, pounding discos, and lots of sex. Urban gay communities in such cities as New York and San Francisco were magnets that drew men from America's small towns everywhere. The promise of acceptance and belonging was as alluring and exciting as the testosterone that seemed to ooze from the very pavement of streets with names like Christopher and Castro. Amidst the drugging, dancing, and fucking, political activists struggled to remind gay people that they would remain second-class citizens until they pulled together to fight the government for their civil and human rights—just as they had fought the police at the Stonewall Inn for their constitutional right to assemble, and the medical establishment for the right to live without the stigma of being considered “sick.” As the party wore on, the glitter wore off for some men who wanted “gay” to mean something more than second-class, sex-crazed, and diseased. But the viral seed had already been sown right along with all those wild oats.

ONE

In 1973, Arnie Kantrowitz was riding high on a wave of gay pride, sexual freedom, and political possibility. As a charter member and former vice president of New York City's Gay Activists Alliance, this self-described "nice Jewish boy" from Newark, NJ, had found within himself a previously unknown self-confidence bolstered by the community he helped to create with his fellow activists in GAA.

That year Kantrowitz wrote an op-ed piece for the *New York Times* which served notice on the world that this young gay man and many others like him were prepared, at last, to stand up for themselves with dignity and without shame.

Kantrowitz recalled thinking at the time, "Yes, we could hide if we wanted to, but that bothered us and we would no longer accept that. So we elected to be open and face the oppression that would come with it because that was more dignified than being frightened and hiding."¹

Kantrowitz also moved to New York's Christopher Street in 1973, after living for two years with fellow GAA members in a commune in SoHo. Now he basked in the revolutionary spirit of freedom that suffused the air of Greenwich Village with possibilities for all sorts of conquests—sexual, political, and, most important, the chance for a coup de grâce in the lifelong internal battle fought by most American gay men against the guilt and shame of being "different."

¹. Arnie Kantrowitz, telephone interview with author, 22 November 1996.

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In a few short years, gay people had gone from being timorous and furtive to bold and “out.” The change was exhilarating, the camaraderie palpable. Kantrowitz celebrated the new sense of community he found in New York in his 1977 autobiography, *Under the Rainbow: Growing Up Gay*. “Chin held high and hopes higher still,” he wrote, “I declared my solidarity with my people. Solidarity is not just a unioner’s catchword. It is a sense of belonging I have felt to my marrow, a kinship as thick as blood relation.”²

Like many gay people in the early seventies, Kantrowitz had been inspired by the audacity and dignity of the patrons of the Stonewall Inn, who, after years of gratuitous harassment by the police, finally stood up and said “enough.” On the night of Friday, June 27, 1969, New York police raided the Stonewall. As usual, they expected to intimidate the Christopher Street gay bar’s patrons, reminding them once again that they were powerless pariahs in American society.

But the cops got more than they expected when the pariahs stood up to them en masse and refused to play the old game in which they were always the losers. Gay people vented years of rage that night and in the nights of demonstrations that followed the raid. “Ain’t gonna take it no more!” became a gay rallying cry after Stonewall, as much a statement about refusing second-class status in American society as about resisting police harassment whose only purposes seemed to be to mollify politicians and let straight cops feel macho—or possibly even avoid dealing with their own homosexuality.

². Arnie Kantrowitz, *Under the Rainbow: Growing Up Gay* (New York: William Morrow, 1977, expanded and reissued by St. Martin’s Press, 1996), 115.

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Within days, gay New Yorkers organized the Gay Liberation Front, replacing years of polite “homophile” gay organizing with an in-your-face militancy never seen before among gay activists. GLF’s rejection of “society’s attempt to impose sexual roles and definitions on our nature” sparked the imaginations of homosexuals in Los Angeles and San Francisco, where GLF chapters also formed. Within a few months, a group in New York broke off from GLF to form Gay Activists Alliance, focusing only on gay rights and political action, rather than the panoply of leftist issues championed by GLF’s band of gay hippies.

The gay rights movement offered Kantrowitz, and many other gay men and women, not only a sense of belonging but also a political cause in which to channel their youthfully idealistic energy. As Kantrowitz described it, “The gay world was a consuming infatuation, and liberation a vision we were reaching for, a vision of a world in which everyone could be honest, a world without pretending, where men could love men and women love women openly.”³ GAA was a militant, though non-violent, organization working for the civil rights of gay people, often through direct confrontation. GAA members half-jokingly called themselves “an army of lovers,” recalling the legendary band of warriors in ancient Greece known as the Sacred Band of Thebes, chosen for the elite fighting unit because they were homosexual lovers and would defend one another to the death.

The group organized petition drives to repeal sodomy laws, demonstrated against newspapers and broadcast stations over media accounts deemed inaccurate or derogatory, and “zapped” elected officials and political candidates by disrupting public forums and even seizing the microphone.

³. Ibid., 100.

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GAA also continued the Stonewall rebellion's choreographed style of "street theater" (a decade and a half before ACT UP would take it to new levels in its own protests) including open displays of affection by same-sex couples and "gay-ins," in which large numbers of people picnicked and danced together in public parks and open spaces.⁴

Besides GAA chapters that sprang up in cities throughout the country, gay political clubs, mostly Democratic, were also organized at the local level during the seventies. The first was the Alice B. Toklas Democratic Club, formed in San Francisco in 1971. Other early groups included Seattle's Dorian Group, organized in 1972, and the Washington, DC, Gertrude Stein Democratic Club, formed in 1976 as an East Coast counterpart to the group in San Francisco.

The post-Stonewall emphasis on "coming out" meant this army of lovers fighting for gay liberation would have an endless supply of new troops. As historian John D'Emilio has noted, "To come out of the 'closet' quintessentially expressed the fusion of the personal and political that the radicalism of the late 1960s exalted."⁵

Despite the formation of political groups and community organizing at the local level, gay people in the seventies had no sense of a national movement or community. A "national" gay community existed only in the pipe dreams of activists. After political ripples spread across the country from singer and former beauty queen Anita Bryant's successful efforts in 1977 to

4. Warren J. Blumenfeld and Diane Raymond, *Looking at Gay and Lesbian Life* (Boston: Beacon Press, 1988), 302.

5. John D'Emilio, *Sexual Politics, Sexual Communities* (Chicago: University of Chicago Press, 1983), 235.

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overturn a gay rights ordinance in Dade County, Florida, gay activists throughout the country saw a need to step up their community organizing. Again, though, the organizing was at the local level; the goal was simply to stamp out the antigay brush fires that Bryant's "Save Our Children" campaign had ignited in other states. The campaign represented one of the earliest organized antigay drives by right-wing religionists—it would hardly be the last, and certainly not the most hate-filled.

Until Anita Bryant's anti-gay campaign, the gay rights movement was little more than a loosely connected ragtag band of committed individuals scattered throughout the country. Paul Boneberg, at the time vice president of the gay student union at the University of California in San Jose, later a prominent AIDS activist in San Francisco, said, "When I began doing gay politics in the mid-seventies, I would suspect there were 100 people [engaged in gay political organizing] in the country, and if you knew those 100 people then you knew everyone who was doing lesbian and gay politics in America. Of those people, maybe two were employed—and not very well employed—in struggling organizations."⁶ Bryant's campaign served notice that gay people had best wake up to the growing threat from the emerging "Christian" right.

Gay organizing in California was further catalyzed when Bryant protégé State Senator John Briggs in 1978 launched a statewide referendum, Proposition 6, known as the Briggs Initiative, that would have prevented gay people from working in public schools. The state coordinator for Briggs was Lou Sheldon, founder and chairman of the rabidly homophobic Traditional Values Coalition.

⁶. Paul Boneberg, interview with author, Washington, DC, 17 August 1995.

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As is still the case, it was only when gay people realized that politics truly has personal ramifications—in this case, the risk of being barred from a job—that they joined the budding community's political efforts. Even ordinary, non-political gay people joined the effort to fight the Briggs referendum.

San Francisco *Chronicle* reporter Randy Shilts wrote, "Gays who had come to San Francisco just to disco amid the hot pectorals of humpy men became politicized and fell into new organizations with names like Save Our Human Rights and Coalition for Human Rights. No longer was the gay movement the realm of offbeat liberation fairies...but a necessary response to a clear and present danger."⁷

In November 1978, the Briggs initiative was defeated at the polls. That same month, San Francisco was rocked by the assassinations of Mayor George Moscone and openly gay city supervisor Harvey Milk.

On November 27, 1978, Milk's fellow supervisor Dan White shot and killed Moscone and Milk in their offices at City Hall. Forty thousand people gathered that night for a candlelight vigil to honor the slain leaders. When an all-heterosexual jury found White guilty of voluntary manslaughter (his attorneys used the now-infamous "twinkie defense" to argue that White's mental capacity had been diminished by eating junk food) and the judge sentenced him to just seven years and eight months in prison with a chance for parole after only five years, the gay community exploded in rage.

⁷. Randy Shilts, *The Mayor of Castro Street: The Life and Times of Harvey Milk* (New York: St. Martin's Press, 1982), 160.

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After the verdict was handed down, about three thousand gay demonstrators marched on City Hall the evening of May 21, 1979, chanting, "We want justice!" and "He got away with murder!" A dozen police cars were burned, one hundred sixty people, including fifty policemen, were injured, and about \$1 million in damage was inflicted.

"Society is going to have to deal with us not as nice little fairies who have hairdressing salons," said Harry Britt, who succeeded Harvey Milk as supervisor, "but as people capable of violence."

Meanwhile, the police celebrated the verdict. Shouting "Fucking faggots!" they trashed the gay bars in the Castro area.⁸

While the mainstream press condemned the gay rioters, the gay press throughout the country was far more sympathetic. An editorial in the *San Francisco Sentinel* concluded, "If our justice system allows for a Dan White, it must also allow for rioters." As Rodger Streitmatter notes in his history of the gay press, an article in *Seattle Gay News* following the assassinations "left no room for doubt that lesbian and gay America was a single community united in its grief at the loss of a magnificent leader."⁹

The unity among the gay press on the assassinations in San Francisco and the ensuing riot, as well as the press's sup-

⁸. Leigh W. Rutledge, *Gay Decades* (New York: Penguin Books, 1992), 139.

⁹. Roger Streitmatter, *Unspeakable: The Rise of the Gay and Lesbian Press in America* (Boston: Faber and Faber, 1995), 222.

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port for successful local efforts to resist antigay spinoff organizations associated with Anita Bryant's "Save Our Children" campaign, went far toward creating a sense of belonging to a cause that extended across the country among the many otherwise unaffiliated local gay and lesbian communities. A spokesman for Boston's *Gay Community News* said in 1979, "The greatest success of the gay press has been to foster community."¹⁰

The first gay political group to take a national focus was the National Gay Task Force, which was formed in New York City in 1973. Now called the National Gay and Lesbian Task Force, or NGLTF, the group since 1986 has been based in Washington, DC According to the task force's founding codirector, Bruce Voeller, its mission was "to reeducate society, including its homosexual members, to esteem gay men and women at their full human worth and to accord them places in society which will allow them to attain and contribute according to their full human and social potential." In response to Anita Bryant's "Save Our Children" campaign, the task force launched its own national education program, underfunded but right on the money, which it called "We Are Your Children."¹¹

The task force succeeded in getting a gay rights measure introduced into Congress when New York Representative Bella Abzug sponsored a bill on March 23, 1975, that would prohibit discrimination based on sexual or affectional preference. The bill languished in Congress in the coming years, trotted out annually to collect a few more sponsors but never actually voted on.

¹⁰. Ibid., 219.

¹¹. Blumenfeld and Raymond, 311.

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Other than its involvement with this one bill, NGLTF didn't have an ongoing presence in Washington in the 1970s. In fact, it wasn't until 1978 that there was even one full-time lobbyist in the nation's capital representing the collective interests of gay people nationwide.

Steve Endean, a young man from Minneapolis, formed the Gay Rights National Lobby in Washington in the fall of 1978. Endean was a forerunner of the kind of coat-and-tie gay and lesbian activists who operate in today's relatively large, well-off national gay rights groups in Washington. In an interview with Edmund White, Endean was quoted as saying, "The movement needs patterned, mature planned programs—not just rage and marches. That energy is good—but it needs to be harnessed. Otherwise, when the anger subsides, it turns out nothing has been accomplished."¹²

After feeling like walking targets of the radical right, and after seeing Harvey Milk literally become an assassin's target, gay people were certainly enraged—and they were ready for a march of historic proportions. On October 14, 1979, more than one hundred thousand gay men and lesbians and their supporters converged on Washington for the first-ever National March on Washington for Lesbian and Gay Rights. A historic National Third World Lesbian and Gay Conference, sponsored by the one-year-old National Coalition of Black Gays, held at the time of the march, brought together gay Blacks, Hispanics, Asians, and Native Americans. Five hundred people attended

¹². Edmund White, *States of Desire: Travels in Gay America* (New York: EP Dutton, 1980), 292.

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the conference, at which poet and author Audre Lorde delivered the keynote address.¹³

Brian McNaught, who at the time wrote a regular column for the gay newspaper in Boston, and would become the mayor's first liaison to the gay community and play a pivotal role in Boston's early response to AIDS in the eighties, described his impressions of the march shortly afterward. McNaught's words spoke for many of the gay men and lesbians at the march who, for the first time in their lives, felt a part of a real community, national in scope. "It was like nothing I had ever been a part of before," wrote McNaught. "It was magic. It was spiritual. It was energizing... 'We are everywhere,' we chanted as we marched to the beat of kazoos and tambourines. 'We are everywhere,' we screamed as we danced and skated and skipped like children. We embraced each other with shiny-faced grins of excitement. We renewed each other with winks and squeezes and outstretched arms. 'We are everywhere,' we insisted, 'and we will be free.'"¹⁴

Eric Rofes, who in the eighties would lead the world's largest gay organization (the Los Angeles Gay and Lesbian Community Center) and then one of the most renowned AIDS service organizations (San Francisco's Shanti Project), in the late seventies was a member of a Boston activist group known as the GCN collective (from *Gay Community News*, a leftist gay newspaper)—a group that would produce a number of nationally prominent gay leaders. As one of the key organizers of the 1979 march, Rofes recalled that in 1979, "your typical gay per-

¹³. Sidney Brinkley, "Black Gay History in the Making," *Washington Blade* (7 February 1997), 12.

¹⁴. Brian McNaught, *On Being Gay* (New York: St. Martin's Press, 1988), 59–60.

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son wasn't involved in gay politics." What's more, he added, "The typical gay political person was involved locally. It was a tough argument to make to get people to understand the need for a national movement."

A lack of state-level gay organizations meant that even within individual states, local groups typically didn't work with others in neighboring communities. The energy and commitment that organizing the national march required of Rofes and the others who pulled it together can't be overstated.

The outcome, though, was an increasingly national sense of gay solidarity. As Rofes told me, "The challenge of that march, and I think the accomplishment of that march, was to create a foundation for awareness on the part of your ordinary movement gay person that there were national issues of importance."¹⁵

Of course there is a substantial gap between awareness of national issues and preparedness for a major catastrophe like AIDS, as Rofes hastened to point out about the epidemic then on the verge of erupting among gay men. "This wasn't a disease visited upon a highly organized, powerful national movement," he emphasized. "The march was both a key trigger for what little national networks were being established at the start of the epidemic, and also a good bellwether of how unorganized we were and how little interest there was in a national movement."¹⁶

Urvashi Vaid, another member of the *GCN* collective, called the 1979 march "perhaps our biggest cultural success to date."

¹⁵. Eric Rofes, telephone interview with author, 21 June 1996.

¹⁶. *Ibid.*, 7 July 1995.

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But she noted that the end of the 1970s marked the beginning of a period of political losses spurred by the rise of an organized antigay opposition. Nevertheless, said Vaid, “the same decade saw gay and lesbian culture, community, and life breaking new ground.”¹⁷

¹⁷ Urvashi Vaid, *Virtual Equality: The Mainstreaming of Gay and Lesbian Liberation* (New York: Anchor Books, 1995), 67.

TWO

For many gay men, the seventies were a time of great possibility as they joined others like themselves in major cities to carve out a place where they could be open about who they were and feel safe from the hatred that oppressed them as American society continued to force them to the margins of its awareness. Some were fortunate to find acceptance even among heterosexuals, and bonds were formed that would become stronger in the tribulations of the years ahead. Nowhere was there a greater willingness by both gay and heterosexual people to reach out and care for one another than in San Francisco, where a visitor might leave his heart and residents could find their heart's desire in the city's scenic beauty and air of openness and acceptance.

After arriving in San Francisco in 1971, Armistead Maupin said he was "shocked to discover that there were straight men and women who were utterly blasé about the fact of homosexuality." Both heterosexual and homosexual people had long been attracted to the gentle city by the bay. Maupin who portrayed life in 1970s San Francisco in his colorful and well-loved *Tales of the City* series of novels, added that because of the acceptance of differences among people in San Francisco, coming-out for him meant living as an openly gay man in the world at large. "It had nothing to do with burying myself in a ghetto and surrounding myself with my own kind. There were enough people here not like me who accepted me [so] that I was able to feel good about myself."¹⁸

¹⁸. Armistead Maupin, telephone interview with author, 23 December 1996.

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For people like Maupin and his friends, the freedom they enjoyed in San Francisco in the seventies meant they could build alternative “families” and a true community. He points out that when AIDS struck the city, “it would have been even worse than it was if we didn’t have those families in place.”

Unfortunately, albeit predictably, it wasn’t the domestic and community-building aspects of gay life that the news media focused on in the years before AIDS. Given the media’s penchant for the anomalous and outré, Americans whose impressions of gay people came only from what they read in magazines and saw on television could easily believe that all gay people dressed in drag or leather, took drugs, copulated in public parks, and, for all they knew, probably kept Dorian Gray-like portraits hidden in the attic to deflect from their youthful faces the ravages of a debauched lifestyle.

In an April 26, 1980, *CBS Reports* news special about gay people in San Francisco called “Gay Power, Gay Politics,” CBS reporter George Crile asked gay activist Cleve Jones, “Isn’t it a sign of decadence when you have so many gays emerging, breaking apart all of the values of a society?” Although a media standards board later acknowledged that the show was biased against homosexuals, the impressions it conveyed were damaging. Armistead Maupin had played host to the CBS news team, showing them around the city and explaining the many facets of gay life. But he said, “I had no idea they were doing a hit piece.”

It certainly hit its mark. As Urvashi Vaid puts it in *Virtual Equality*, “The tone of the CBS show was alarmist and seemed to suggest that gays would soon head out of the Castro, out of the gay bars and bushes that had been their ‘traditional’ do-

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main, and into government offices, boardrooms, and, eventually, the playgrounds of America.”¹⁹

Looking back at the pre-AIDS image of gay people painted by the media, Maupin said, “The thing that annoys me most is the revisionist attitude that gay people didn’t discover the bonds of family until AIDS and impending death forced it upon them. Nothing could be further from the truth. There were, as early as the mid-seventies in San Francisco, gay lawyer groups, gay doctor groups, gay needlepoint groups, gay sports teams, and people forming viable, loving families.”²⁰

Throughout the country, notes John D’Emilio, there were already more than one thousand gay and lesbian organizations by the mid-seventies. “Activists,” he writes in *Sexual Politics, Sexual Communities*, “created newspapers, magazines, health clinics, churches, multipurpose social centers, and specialized businesses—in short, a range of institutions that implied the existence of a separate, cohesive gay community.”²¹

Pat Norman, a veteran Black, lesbian, and human rights activist in San Francisco, recalled her experience of working with the city’s Gay Counseling Service in the early seventies. The transition from in-the-closet-and-ashamed to out-and-proud was not an easy one for many (if not most) gay people to make, and psychotherapy often became an important tool in adjusting to their newfound freedom. “It was a group of young gay men and me,” said Norman, “who set up services outside the [mainstream] institutions in order to help people come out, deal with

¹⁹. Vaid, *Virtual Equality*, 210–11.

²⁰. Maupin interview.

²¹. D’Emilio, *Sexual Politics*, 2.

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relationship issues, depression, anxiety, their problems within that particular era in coming out.” She added, “It seemed to us then that everybody was coming out. It was a revolutionary time.”²²

The revolution wasn’t only in the healing of psychological wounds, but in the increasing boldness of gay people to assert their rights as American citizens. One of the most important battles in the revolution was against unprovoked harassment and entrapment by police, an alarming feature of urban gay life in the years before Stonewall. John D’Emilio told me that the combination of a decline in police harassment and an increase in gay people coming out of the closet made for “a pretty vibrant urban sexual subculture of gay men that actually was a continuation of things that were going on in the sixties.” Earlier gay subcultures could be found in places like San Francisco and New York, but they were hidden behind shaded windows. “Now,” said D’Emilio, “the doors were open and people were half in and half out of the bar; it was part of public life, rather than just closeted life.”²³

The revolutionary spirit of freedom drew many gay men westward to San Francisco. A sense of expectation, adventure, and the chance finally to fit in somewhere gave the city the allure of a “gay mecca,” as the city had become known by the seventies. As Randy Shilts observed, “The promise of freedom had fueled the greatest exodus of immigrants to San Francisco since the Gold Rush.” Between 1969 and 1973, he reported that at least nine thousand gay men moved to San Francisco,

22. Pat Norman, telephone interview with author, 12 September 1995.

23. John D’Emilio, interview with author, Washington, DC, 24 May 1996.

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followed by twenty thousand more between 1974 and 1978. “By 1980,” said Shilts, “about five thousand homosexual men were moving to the Golden Gate every year. The immigration now made for a city in which two in five adults were openly gay.”²⁴

For thousands of gay men, San Francisco represented safety, literally a refuge from the insults, beatings, and moral condemnation they had suffered throughout their lives merely for being homosexual. Vast numbers of them made the Castro district the center of their world. Even today, one can still hear the intersection of Castro and Eighteenth streets, the heart of the area, referred to as “the crossroads of the gay world.”

A 1970 pamphlet called *Refugees from Amerika: A Gay Manifesto*, written by gay liberationist Carl Wittman, described San Francisco as “a refugee camp for homosexuals.” After fleeing small towns, blackmailing cops, families who disowned or “tolerated” them, after being thrown out of schools and the armed services, fired from jobs, beaten by punks and policemen alike, Wittman wrote, gay people “have formed a ghetto, out of self-protection.”²⁵

“Some called it Mecca,” Randy Shilts wrote in *The Mayor of Castro Street*, his 1982 biography of Harvey Milk, “but to most

²⁴. Randy Shilts, *And the Band Played On* (New York: St. Martin’s Press, 1987), 15.

²⁵. Carl Wittman, *A Gay Manifesto*, reprinted in Karla Jay and Allen Young, eds., *Out of the Closet: Voices of Gay Liberation* (New York: Douglas Books, 1972), 330–42.

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gays it was nothing short of Oz, a place they had never hoped to see in their lifetimes.”²⁶

Gay men, however, did not universally regard the ghetto as a positive development.

In an interview with Edmund White in the late seventies, then *Advocate* publisher David Goodstein—who was appalled by what he considered Harvey Milk’s lack of finesse and the Castro crowd who strongly supported him—described two large groups of gay men in San Francisco. One, he said, consisted of men over thirty who had lived in the city at least a decade, served on opera committees, worked in the professions, showed an interest and concern for the community. “They’re not so different from gays everywhere,” he said, “though more of them here are out of the closet and they’re better organized than in most places.”

The second group Goodstein described was the so-called “Castro clones,” gay men who, as Goodstein put it, “are convalescing in the ghetto from all those damaging years in Podunk.” He said they were a rough crowd, hanging out like teenagers, drinking too much, taking too many drugs, fucking day and night, infecting each other with venereal diseases, “and of course radical politically.” Worst of all, said Goodstein, “They have a *shtetl* consciousness—you know, like the Jewish ghetto. They patronize Castro Street businesses; in fact, they seldom leave the area.”²⁷

Harvey Milk epitomized the men Goodstein disdained, even if Milk did love the opera. In fact the man his neighbors called

²⁶. Shilts, *The Mayor of Castro Street*, 175.

²⁷. White, *States of Desire*, 34–35.

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the “Mayor of Castro Street,” openly and proudly championed gay-owned businesses in the ghetto. Milk, of course, owned Castro Camera, at 575 Castro Street, in the heart of the ghetto. His shop was an unofficial community center, a welcoming space for gay men newly arrived from small towns across America. It’s where Cleve Jones, who would become one of gay America’s boldest visionaries in the years ahead, found a friend and mentor in Harvey Milk.

Even if Goodstein’s observations were accurate, they smacked of economic elitism. And criticism of the rampant promiscuity in the gay ghetto was ironic coming from the publisher of a newspaper supported largely by advertising paid for by bathhouses and other sexual services that fostered the very activities he deplored. The ghetto certainly was teeming with refugees, but merely condemning or mocking them, as Goodstein did, failed to address the oppression that these men felt had forced them there in the first place—and did nothing to aid their “convalescence.”

Shut away from a disapproving world, the ghetto flipped an angry middle finger at the society that had forced its creation, adopting its own value system and asserting a sense of pride that was far preferable to the shame that gay men had been told was their lot in life.

White observed in *States of Desire* that in San Francisco “gays constitute such a numerous and well-organized minority [an estimated 20 percent of the city’s 335,000 registered voters were gay] that the life of the city is to a remarkable degree within their power to shape.”

In the gay ghetto, however, the reverse was true: the lives of gay men there were shaped by the life and values of the ghetto. As Randy Shilts put it, “Gays no longer came to the Castro to

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create a new lifestyle, they came to fit into the existing Castro Street mold.”²⁸

White’s own final take on San Francisco was that it was “where gay fantasies come true.” But, he said, “the problem the city presents is whether, after all, we wanted these particular dreams to be fulfilled—or would we have preferred others? Did we know what price these dreams would exact?”²⁹

The visibility of gay men in the ghettos made them easy targets for homophobes, capitalists, and social diseases that thrived on the vulnerability of people trying to find their place in the world. Describing the men who filled the ghettos, and whose minds were in turn filled by the ghetto way of thinking, Canadian writer Ian Young notes that few of these “refugees” had the skills they needed for emotional equilibrium—or even survival—in the big city. “Isolated gay boys from small towns,” he said, “they arrived in the Village or the Castro lacking the discernment and abilities necessary to maintain real friendships or meaningful ties.”³⁰

Being smart capitalists, the owners of bars and bathhouses—frequently heterosexual and affiliated with the Mafia—gained control over the attitudes, behaviors, and spending habits of their gay patrons. They created a “need” for their services and then met that need in the dark and drug-addled anonymity of their establishments. The proliferation of these outlets in the seventies, and the pressures from peers and ad-

²⁸. Shilts, *The Mayor of Castro Street*, 226.

²⁹. White, *States of Desire*, 28–64.

³⁰. Ian Young, *The Stonewall Experiment* (London: Cassell, 1995), 63.

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vertising in the gay press alike to avail oneself of them as socially acceptable alternatives to, say, relationships, led many gay men to define their lives in the very terms with which heterosexuals often stereotyped them. In this truncated view of homosexuality, one's attitude toward promiscuity became a kind of litmus test for how "out" he was; if one was uncomfortable with promiscuity, went the reasoning of the day, it was because he hated being gay.

How far gay men, at least the segment of them in the urban ghettos, had strayed from the visionary ideals of gay pioneers like Harry Hay, founder in 1950 of the nation's first "homophile" organization, the Mattachine Society, in Los Angeles! Though perhaps more cerebral than most, Hay had laid a fairly solid foundation for gay men to stand on in knowing who they were: homosexuals were unique, he asserted, and they have something important to offer to humanity in general. Hay believed that the gender of their sex partners was not the only thing that distinguished gay men from heterosexuals. Sex was certainly an important part of being gay for Hay, but it was years from becoming the part and parcel of gay ghetto life it became in the seventies.

"Who are gay people?" asked Hay. "Where have we been in history? What might we be for?" Hay spoke of homosexuals as "spirit people," who, throughout the ages, had served society through their roles as "messengers and interceders, shamans of both genders, priestesses and priests, imagemakers and prophets, mimes and rhapsodes, poets and playwrights, healers and nurturers, teachers and preachers, tinkers and tinkers, searchers and researchers."³¹ Hay believed that gay peo-

31. Harry Hay, "A Separate People Whose Time Has Come." In Mark Thompson, ed., *Gay Spirit: Myth and Meaning* (New York: St. Martin's Press, 1987), 279–91.

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ple had something special to teach nongay people about human life, and for that reason should be nurtured rather than reviled, by society. He postulated that “gay people represent a genetic mutation of consciousness whose active fostering is now required for human survival.”³² It hardly seems likely that the “shtetl consciousness” of the gay ghetto was the “mutation” that Harry Hay had in mind.

Gay writer John Rechy, author of the extraordinary 1963 novel *City of Night*, called homosexuals “sexual outlaws,” forced into a life at the social fringe whose main feature was promiscuity. “In this context, the sexual outlaw flourishes,” wrote Rechy in his 1977 book *The Sexual Outlaw*. “The pressures produce him, create his defiance. Knowing that each second his freedom may be ripped away arbitrarily, he lives fully at the brink. Promiscuity is his righteous form of revolution.”³³

The flaw in this assessment, though, is that true revolutionaries don’t just rebel, they push to bring about a society molded according to their vision of how things ought to be. The “sexual outlaw” simply acted out of the pain of his pariah status without having anything other than a very myopic vision that couldn’t see beyond the walls of the ghetto.

The lifestyle offered in the urban ghettos was, as Ian Young puts it, “the ultimate consumer product—a permanent sex holi-

³². Stuart Timmons, *The Trouble With Harry Hay, Founder of the Modern Gay Movement* (Boston: Alyson Publications, 1990), 292.

³³. John Rechy, *The Sexual Outlaw: A Documentary* (New York: Grove Press, 1977), 31.

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day.”³⁴ And it wasn’t only the “clones” who enjoyed this holiday. Even politically active men who were working for gay liberation frequently equated freedom with the right to have prodigious amounts of sex with anyone, anytime, anywhere.

Arnie Kantrowitz, who had found personal liberation in his work in the gay rights movement, said, “I came to define myself by my sexuality. And I valued myself by my sexuality. Sex came first.” When he developed syphilis, he recalled, he wept because he had to stop having sex for a while. “Who would I be if I wasn’t going to be the hot sex partner, the great pursuer or pursued?” he wondered.³⁵

After moving from Michigan “to be gay” in San Francisco in the seventies, Chuck Frutchey said, “the sex, the political organizing, they were really jumbled up, there wasn’t a lot of separation between them” Frutchey and many others believed that “gay lib” would benefit everyone by liberating sexuality from American puritanism and integrating it into ordinary life. “In the seventies,” said Frutchey, “people didn’t see any sort of philosophical clash between holding down their job during the day, volunteering for some political activity in the evening, and going to a bathhouse with people they met at the volunteer activity at night.”³⁶

Michael Callen, a musician who would become one of the best-known and longest-surviving people with AIDS in the country, recalled, “At first, I had been promiscuous because the

³⁴. Young, *The Stonewall Experiment*, 64.

³⁵. Kantrowitz interview.

³⁶. Chuck Frutchey, telephone interview with author, 14 August 1995.

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only information I had about gay men was that we were all promiscuous *by nature*.” After discovering gay liberation, he “proudly and defiantly” celebrated the promiscuity that mainstream society so disapproved of. “During the seventies,” said Callen, “I considered myself a lowly private doing battle on the front lines of the sexual revolution. I joked that I was a fast-food sex junkie. For me, being gay *meant* having lots of sex.”³⁷

For many urban gay men, the venues that facilitated sex—from the decaying piers at the end of Christopher Street, to the dark backrooms in gay bars, to the bathhouses and sex clubs—served as community centers of sorts: the more you frequented them, the more “social” you were (and, not coincidentally, the more “social diseases” you likely contracted).

The Canadian gay magazine *The Body Politic* observed, “Promiscuity knits together the social fabric of the gay male community.” The catch to this way of thinking was that “community,” as it is usually defined, presumes at the barest minimum that people know one another’s names. Anonymous sexual encounters in the dark, while they may have inspired a feeling of priapic brotherhood with other men in the same situation, were hardly the stuff of which a real community is made.

What Arnie Kantrowitz called “the freedom of facelessness” flourished in the darkened backroom bars and the baths. As gay sexuality was commercialized in the seventies, a range of sexual establishments arose to cater to increasingly specialized tastes. For many, the baths were places where a man could be held, if that’s what he needed, or where he could test the limits of bodily endurance if that was his inclination. For men who were not open about their homosexuality, the baths might be

³⁷. Michael Callen, *Surviving AIDS* (New York: HarperCollins, 1990), 3–4.

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the only place they felt free to act on their desire for other men. Because of this anything-goes atmosphere, various envelopes were pushed regularly—and far.

There was also an air of unreality about the baths, at least partly intentional. The early seventies image of gay men in towels sitting around listening to Bette Midler, with Barry Manilow on the piano, all of them surrounded by straight people in evening dress who came for the show at the Continental Baths in New York (one of the reasons Midler was embraced early and strongly by the gay community) seems unreal, yet it happened.

But the establishments themselves, with their dimly lit hallways, rows of small cubicles, orgy rooms, nap rooms, steam rooms, and whirlpools, were also refuges for many gay men from the struggle that was their lives. As Kantrowitz recalled, “It was always night at the baths, protected from the reality outside the door by a thick layer of gay imagination that sealed us in a secure environment as if we were in a huge magic theater where we could forget for a few hours what society thought of us.”³⁸

Armistead Maupin recalled the baths in the early seventies with wistfulness. He called them “places of extraordinary communion and coziness.” He explained, “There was still enough of the old generous hippie spirit afoot to keep things from being too cold-blooded and mechanical.” Maupin never saw the promiscuity he enjoyed back then as a bad thing, even after AIDS came along. “I was never ashamed of my promiscuity,” he said, “because I saw it as a fundamentally innocent and wonderful and human thing. And because I had spent way too

³⁸. Kantrowitz, *Under the Rainbow*, 133.

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many years suppressing my sexuality, I had no intention of forbidding myself that pleasure any longer.”³⁹

But by the end of the seventies, Maupin noted that there had been a change in the urban gay sex culture as the seventies progressed and the baths drew thousands of men a week in some cities. “As the bathhouses and bars became more institutionalized,” he said, “they became lonelier places, and much less fulfilling.”⁴⁰

In New York, the Mine Shaft in the late seventies and early eighties was the bar-cum-sex-club that, as Douglas Sadownick notes, “almost every survivor from the seventies points to as a symbol of the fearlessness with which some gay men broke sexual taboos.”⁴¹ Every possible fantasy—except, of course, the fantasy of sex with love—was enacted within the walls of the Mine Shaft, from being pissed on in a bathtub to being whipped by a “master” while chained to a wooden cross. The club’s denizens included far more than just ghetto “clones.” In my own earliest experience of gay life in New York, circa 1980, I recall affluent gay men excusing themselves from Upper West Side dinner parties, and, bedecked in the requisite black leather jackets and chaps, heading downtown for “dessert” at the Mine Shaft.

³⁹. Maupin interview.

⁴⁰. Maupin, quoted in Lon G. Nungesser, *Epidemic of Courage: Facing AIDS in America* (New York: St. Martin’s Press, 1986), 215.

⁴¹. Douglas Sadownick, *Sex Between Men: An Intimate History of the Sex Lives of Gay Men Postwar to Present* (San Francisco: HarperSanFrancisco, 1996), 123.

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One of the esoteric activities that became popular among some of the men who frequented the Mine Shaft went by names such as “hand-balling,” “fisting,” and “fist-fucking.” After an elaborate ritual involving douching and imbibing enough drugs to deaden both the pain of the act and the better judgment that might remind them of its potential deadliness, men would submit to the invasion of their rectum by another man’s fingers, hand, and even forearm. Ian Young notes, “fisting was the ‘new’ sexual act of the 1970s” and “a characteristic activity of ghetto gays from the mid-1970s on.”⁴² Fisting invariably involved multiple snorts of “poppers,” the amyl and other nitrite inhalants that became ubiquitous aphrodisiacs in the sex life of the ghetto.

In a bit of perverse irony, the patent on amyl nitrite, the medicinal form of the inhalant originally used by angina patients—packaged in capsules that were “popped” to release their vapors—was owned by none other than British pharmaceutical giant Burroughs Wellcome.⁴³ Few would recall this fact in the early eighties when poppers became one of the first suspected causes of AIDS, or later in the decade when Burroughs was licensed to distribute AZT, the first approved treatment for AIDS. As Larry Kramer put it, “The company that made money by ‘enabling’ promiscuity, as it were, is now making a fortune by trying to stem its aftermath.”⁴⁴

⁴². Young, *The Stonewall Experiment*, 170.

⁴³. Ibid., 104.

⁴⁴. Larry Kramer, “A Good News/Bad News AIDS Joke,” *New York Times Magazine* (14 July 1996), 28.

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As the seventies wore on, the gluttonous sex scene began to wear thin for some men. For Arnie Kantrowitz, the realization that he derived as much pleasure from his writing as from sex provided something of a second liberation. "I found it more gratifying to finish a piece of writing than to have gotten laid," he said. "I found myself going to the baths, or the Mine Shaft in the old days, and I used to keep a pad in my pocket and take notes by the light of the cigarette machine because writing was exciting. After a while, I realized that the writing was just as much of a satisfying high as the sex was."⁴⁵

Other men who had participated enthusiastically in the life of the ghetto had grown tired of its anonymity and inverted values. They questioned why membership in the gay community had come to require that one be alienated from his family, take multiple drugs, and have multiple sex partners, dance all night at the "right" clubs, and spend summer weekends at the "right" part of Fire Island.

Rather than providing genuine liberation, gay life in the ghettos had created another sort of oppression with its pressure to conform to social expectations of what a gay man was "supposed" to be, believe, wear, and do. The "safety" offered by the ghetto began to seem too artificial, with the price of "belonging" one's renunciation of the belief that there could be fulfilling gay life outside the ghetto. As Kantrowitz put it, "We had come in search of protective anonymity, and we had all wound up in the same gigantic closet."⁴⁶

Twin bombshells exploded over the New York ghetto in 1978, when two gifted writers focused their sights on a world of

⁴⁵. Kantrowitz interview.

⁴⁶. Kantrowitz, *Under the Rainbow*, 119.

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romantics whose minds had been anesthetized by too many drugs, and whose hearts desire for love had been deadened by settling time after innumerable time for mere sex.

In his first novel, *Dancer from the Dance*, Andrew Holleran told the story of the handsome and enigmatic Malone, described by Holleran as a “prisoner of love.” Fixing his literary “gun” on the gay disco scene, with its fixation on youth and drugs, Holleran described the dancers in one of Malone’s favorite hangouts: “Many of them were very attractive, these young men whose cryptic disappearance in New York City their families (unaware they were homosexual) understood less than if they had been killed in a car wreck. They were tall and broad-shouldered, with handsome, open faces and strong white teeth, *and they were all dead* [my emphasis].”⁴⁷

In the summer these men headed out of the city to Fire Island, a spit of land off the Atlantic side of Long Island, and one of the loveliest beach resorts imaginable. The island and the beautiful men it drew, the drugs they took, and the sex they had were mythic among homosexuals. As Holleran described it, “Fire Island was for madness, for hot nights, kisses, and herds of stunning men.”⁴⁸

But Malone was growing tired of the madness and dreamed of more. The constriction of the ghetto ultimately killed individuality as the men who melded their identities with ghetto life “disappeared in New York City” and its gay demimonde. In the end, at the age of thirty-eight, his golden beauty ripening into middle-aged handsomeness, Malone’s dream of lasting love—

⁴⁷. Andrew Holleran, *Dancer from the Dance* (New York: William Morrow, 1978), 40.

⁴⁸. *Ibid.*, 207.

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the source of his charm and even his identity—is lost in the carnal immediacy of the ghetto. Like his friends, Malone wound up “living on faces, music, the hope of love, and getting farther and farther away from any chance of it.”⁴⁹

Like Malone, many gay men surrendered their dreams of love for the chance to belong in the ghetto world, no matter how exorbitant the price of membership. In his own 1978 novel *Faggots*, Larry Kramer asked whether the price of membership hadn’t become too high—or whether membership was even desirable. On the eve of his fortieth birthday, Kramer’s protagonist, Fred Lemish, makes the argument that his creator would continue to make for years: “Why do faggots have to fuck so fucking much?!...it’s as if we don’t have anything else to do...all we do is live in our Ghetto and dance and drug and fuck.” Lemish warns his philandering boyfriend, Dinky, to slow down “before you fuck yourself to death.”⁵⁰

Gay reviewers savaged the book, accusing Kramer of betrayal for daring to challenge the “shtetl consciousness” of the ghetto. Gay novelist George Whitmore, writing in *The Body Politic*, urged a boycott of the book. New York’s Oscar Wilde Memorial Bookshop refused to sell it. With the appearance of AIDS three years after its publication, *Faggots* would continue to ignite passionate arguments among some in the gay community who believed that Kramer was gloating that AIDS seemed to deliver into his hands a kind of medical “I told you so.” But Kramer insisted that his main concern had been gay men and their quality of life.

⁴⁹. Ibid., 219.

⁵⁰. Larry Kramer, *Faggots* (New York: Random House, 1978), 335, 337.

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If Kramer had touched a nerve with *Faggots*, an op-ed article he wrote for the *New York Times* shortly after the novel's publication practically caused a nervous breakdown among gay activists. Having just returned from a trip to San Francisco to promote his book—coincidentally the week that Mayor George Moscone and gay supervisor Harvey Milk were murdered and the gay community mounted a spontaneous and massive candlelight vigil to mourn them—Kramer was impressed by the solidarity and political activism of the city's gay community. "I am back in New York, missing, very much, the sense of community I felt in San Francisco," wrote Kramer. "I call several of my friends, but no one is home. I know that most of my friends are at the bars or the baths or the discos, tripping out on trivia." This much was familiar from his just-published novel, but Kramer went one step further. "The City Council was right," he continued, referring to a recently defeated gay rights ordinance. "We are not ready for our rights in New York. We have not earned them. We have not fought for them."⁵¹

But where had Kramer been all those years when other gay people were putting themselves on the line to stand up for their rights? Although he had never joined a gay political organization, Kramer had certainly participated in the scene he now condemned. His most vocal critics dismissed Kramer's criticism as nothing more than bitterness from his disappointment that the ghetto life hadn't provided him with the lover he longed for. "People felt betrayed," said Arnie Kantrowitz. "He was asking us to alter our behavior so we could demand a legitimacy that not all of us were sure we wanted. Some of us just wanted the government and police and our employers off our backs so we could be free from prying eyes and hypocritical judgments. We

⁵¹. Larry Kramer, *Reports from the holocaust: The Making of an AIDS Activist* (New York: St. Martin's Press, 1997), 102.

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were like children playing a new game, and we weren't ready to assume the responsibility of adulthood."⁵²

Therein lay the problem, as Kramer saw it. But saying so, and in public at that, earned Kramer a pariah status within a community of pariahs. He was undeterred, however, and his message would remain the same in the decades ahead.

After recalling the uproar over *Faggots*, Kramer said in a 1995 interview, "Why are we so perennially focused on our dicks? It's a very peculiar 'community' that uses sexuality as the sole yardstick of action and thought and everything. It just seems to me so limiting and blind."⁵³

Driven to be an outsider—a role he seemed to relish—Kramer's years of self-imposed "exile" after *Faggots* came out would, with the appearance of AIDS, provide the outsider with a second walk-on role, the one he lived for and the name by which he came to refer to himself in the plague years: Cassandra. Like the mythic daughter of King Priam warning of the downfall of Troy, Kramer seemed gifted with prophecy but was fated never to be believed.

Kramer wasn't alone in resisting the view that gay men are nothing more than constellations of sexual impulses. Even among some who were active participants in the sex- and drug-filled ghetto scene, the time seemed right to move on to another

⁵². Arnie Kantrowitz, "An Enemy of the People," in Lawrence D. Mass, ed., *We Must Love One Another or Die: The Life and Legacies of Larry Kramer* (New York: St. Martin's Press, 1997), 102.

⁵³. Larry Kramer, interview with author, New York City, 4 March 1995.

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er phase of their gay lives that didn't include some of the old ways that had become precisely that, old.

Arnie Kantrowitz, a veteran of both the political and sexual revolutions of the seventies, said at the end of the decade, "I had explored my sexual fantasies enough, and I was ready to return to the life I had once led, but as a new person." Even on the street that symbolized gay liberation, he said, "More and more tourists are coming to Christopher Street to look, and it isn't as totally gay as it once was, or as glittering. Times change. America is growing up through the resignation of a president and the shaking of its dreams. And I am growing with it."⁵⁴

In a few short years, many shaken dreams, and too many foreshortened lives, would force similar growth in considerably greater numbers of gay men. In the meantime, the party continued. The Saint, the most expensive wholly gay-owned enterprise in the country and perhaps the most famous gay disco ever in New York, opened in September 1980.

The most successful export of gay ghetto culture, the Village People, titillated America with their costumed variations on the macho clone—and sold millions of records. "I'm ready for the eighties," they sang on their 1980 *Live and Sleazy* album, "ready for the time of my life." How very different the eighties and the "time of their life" would look. They could not possibly have imagined it.

⁵⁴. Kantrowitz, *Under the Rainbow*, 189.

THREE

To understand the uneasy relationship between gay people and the American medical establishment, one must look at the medical specialty of psychiatry and its shifting views on homosexuality over the years. From the time psychiatry emerged as a discipline, in the nineteenth century, it offered medical explanations of human behavior that, in earlier times, was explained and evaluated in religious terms. An increasingly secular society looked to psychiatry for guidelines on right and wrong. The religious language of sanctity and sinfulness was translated into the terminology of science.

But the moralism of earlier times carried over into the translation, as psychiatrists spoke of behavior in terms of “normal” and “abnormal.” Behavior that was different from that of the majority was deemed abnormal. Homosexuality, however natural it was for some people, was not merely labeled abnormal, but its difference from the heterosexual “norm” led psychiatrists to condemn it—in terms that may have seemed scientific but that would prove to have less in common with the rationality of science than with the irrationality of prejudice.

“Psychiatry is the devil incarnate!” shouted Frank Kameny, seizing the microphone as he and other gay rights activists “zapped” a major session of the American Psychiatric Association’s 1971 annual meeting in Washington, DC “Psychiatry has

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waged a relentless war of extermination against us,” he continued. “You may take this as a declaration of war against you.”⁵⁵

Kameny, a firebrand of the homophile movement—as the pre-Stonewall gay rights movement was known—decried the injury and voiced the anger of gay men and lesbians who, for decades, had been subjected to electroshock, lobotomy, “conversion” therapy, and commitment to mental hospitals by psychiatrists who believed they were “sick” and in need of cure. Kameny believed that psychiatry’s designation of homosexuality as a mental illness was the prop holding up society’s disdain of homosexuals. Remove it, kick it out, he reasoned, and the walls of discrimination would come tumbling down. Two years later, in 1973, the American Psychiatric Association did remove homosexuality from its official list of mental illnesses. Describing how a combination of science and politics led the APA to change its mind, ethicist Ronald Bayer notes that the APA’s diagnostic change “deprived secular society...of the ideological justification of its discriminatory practices.”

In 1990, the World Health Organization abandoned its definition of homosexuality as an illness. England, the country that gave “the abominable crime of buggery” its name and drove its most famous practitioner, Oscar Wilde, to an untimely death, in 1994 finally stopped treating homosexuality as a mental illness. In 2001, China—whose ancient history included widespread acceptance of homosexuality and no fewer than ten ‘openly bisexual’ emperors—finally acknowledged that homosexuality is

⁵⁵. John-Manuel Andriote, “Shrinking Opposition,” *10 Percent* (Fall 1993), 61. Note that this section of the relationship of homosexuals and psychiatry is based largely upon this article.

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not a mental illness.⁵⁶ Today there are gay-affirmative theories and therapists and hundreds of openly gay and lesbian psychiatrists who enjoy voting representation within the APA's governing bodies. But it hasn't been this way for long.

Many homosexuals wore the pathology label with as much dignity as they could muster, preferring to be labeled sick rather than be considered sinful or criminal, as they had been for hundreds of years. Scientific speculation shuttled between theories of causality and remedies for cure, the beginnings of a preoccupation that continues to this day: What *causes* homosexuality? Nature? Nurture? Genes? Family relationships?

The most influential early theory of causality came from Sigmund Freud, who believed that everyone passes through a homoerotic phase, but that for some reason homosexuals' development is "arrested" during this phase, leaving them stuck with a less than "normal" (i.e., heterosexual) sexual orientation. Still, Freud conceded in a famous letter to an American mother, concerned about her son, homosexuality "is nothing to be ashamed of, no vice, degradation, it cannot be classified as an illness."

Unfortunately, Freud's radical humanism was soon lost on the profession he pioneered—psychoanalysis, the psychiatric specialty devoted to theories of unconscious development—and the view of homosexuality as pathology dominated the psychoanalytic field. In fact, this view remained largely unchanged until recent years in the thinking and practice of U.S. psychoanalysts. Richard A. Isay, the first openly gay member of the American Psychoanalytic Association, notes that the orthodox psychoanalytic view was that "homosexuality is abnormal

⁵⁶. Henry Chu, "Chinese Psychiatrists Decide Homosexuality Isn't Abnormal," *Los Angeles Times* (6 March 2001).

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because it is not heterosexuality.”⁵⁷ This bit of circular logic was also the official position of American psychiatry.

In 1952, the first panel ever to deal with homosexuality at a meeting of the American Psychoanalytic Association, was titled “Perversion: Theoretical and Therapeutic Aspects.” That same year, the American Psychiatric Association published the first edition of the *Diagnostic and Statistical Manual*, its guide to mental disorders, describing homosexuality as a “sociopathic personality disturbance.”

Conveniently ignored by antigay psychiatrists was an expanding body of scientific literature that homosexuals would eventually use to challenge psychiatry on its own terms. Most prominent was the 1948 survey of male sexual behavior by sex researcher Alfred Kinsey and his colleagues. The study shocked the nation with its finding that some 37 percent of (white) men in the United States had engaged in sex with another male to the point of orgasm at some point in their lives. Kinsey noted that attempts to categorize sexual behavior as *either* heterosexual *or* homosexual were pointless because of the complexity of the human animal. Sexuality, he argued, was a continuum, with lifelong, exclusive hetero- and homosexuality at its poles and most people falling somewhere in between, capable of behaving sexually with either males or females under particular circumstances. Kinsey likewise rejected notions of “normal” and “abnormal” sexual behavior.⁵⁸

⁵⁷. Richard A. Isay, MD, *Being Homosexual: Gay Men and Their Development* (New York: Farrar Strauss & Giroux, 1989).

⁵⁸. Alfred Kinsey, *Sexual Behavior in the Human Male* (Philadelphia: W.B. Saunders, 1948).

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Kinsey's points were underscored in 1951, when Cleland Ford and Frank Beach analyzed more than seventy cultures outside the United States. The researchers found that among cultures for which such information was available, forty-nine overtly sanctioned homosexual behavior as natural for some members of the community.

And in 1957, psychologist Evelyn Hooker finally did justice to the notion of scientific objectivity, long missing from research on homosexuality. Earlier psychiatric studies of homosexuality had focused on psychiatric patients, prisoners, patients from mental hospitals, and the military. But Hooker used standard psychological tests to disprove the claims of so-called experts who said they could distinguish the results of nonpatient homosexual from heterosexual subjects. Summarizing her findings, Hooker wrote, "What is difficult to accept (for most clinicians) is that some homosexuals may be very ordinary individuals, indistinguishable from ordinary individuals who are heterosexual."⁵⁹

Gay people slowly began to challenge psychiatry's "scientific" views of homosexuality—and psychiatrists reacted strongly. Edmund Bergler's 1956 book, *Homosexuality: Disease or Way of Life*, infuriated the loosely organized gay community. Bergler blamed Kinsey, whom he derided as a "medical layman," for stirring up homosexuals to the point that "they are now virtually asking for minority status." The psychiatric profession, and the American public who listened deferentially to what these men had to say, turned to people like Irving Bieber and Charles Socarides for a purportedly intelligent opinion on homosexuality.

In 1963, Bieber, a psychoanalyst known for his unsubstantiated claims of "curing" homosexuals, said that he "does not ap-

⁵⁹. Evelyn Hooker, "The Adjustment of the Male Overt Homosexual," *Journal of Projective Techniques* 21 (1957): 18–31.

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prove the attempt by organized homosexuals to promote the idea that they represent just another minority, since their minority status is based on illness.” Socarides, another leading psychoanalyst outspoken in his view that homosexuality constituted “profound psychopathology,” couched his hostility toward gay people in the guise of doctorly concern. He said, “The homosexual is ill, and anything that tends to hide that fact reduces his chances of seeking treatment...If they were to achieve social acceptance, it would increase this difficulty.”⁶⁰ Ironically, in view of his traditional psychoanalytic belief that a distant father is a “cause” of homosexuality, Socarides’ own son, Richard, is a longtime gay activist—and was President Bill Clinton’s liaison to the gay community.

The deference of gay men and lesbians to psychiatric authority began to dissipate in the sixties. The Black civil rights movement, the women’s movement, the antiwar movement, and finally the gay rights movement—all changed America’s preconceptions and shook up its categories of right, wrong, normal and abnormal.

The Mattachine Society of Washington, DC, an early gay rights group led by Frank Kameny, decided in 1965 to let the psychiatrists know that there would no longer be a market in the homosexual community for their “pseudo-scientific” views. The group adopted a resolution asserting that, “In the absence of evidence to the contrary, homosexuality is not a sickness, disturbance, or other pathology in any sense, but is merely a preference, orientation, or propensity, on par with and not different in kind from heterosexuality.”⁶¹ Said Kameny, “We are

⁶⁰. *New York Times*, 17 December 1963.

⁶¹. Franklin E. Kameny, “Emphasis on Research Has Had Its Day,” *The Ladder: A Lesbian Review* (October 1965), 11.

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the experts on ourselves.”⁶² Gay people were getting fed up with being labeled and dismissed as sick and second-class.

In 1970, the executive committee of the National Association for Mental Health declared that homosexual relations between consenting adults should be decriminalized. Within a year, the group’s San Francisco affiliate adopted a resolution saying, “Homosexuality can no longer be equated only with sickness, but may properly be considered a preference, orientation, or propensity for certain kinds of life styles.”

Braced by such affirmation, gay activists began to strike with vehement regularity at the American Psychiatric Association. The late Barbara Gittings, a longtime lesbian activist from Philadelphia, relished the memories of the zaps of the APA’s conventions, beginning in 1970. “A year after Stonewall,” she told me, “a lot of gay people were raring to go.”

Off they went to San Francisco, for the APA’s annual meeting, where they disrupted a session on behavioral therapy. “We said, ‘We want you to talk with us, not about us,’” recalled Gittings.⁶³ Disconcerted by such confrontational tactics, many psychiatrists fled the room.

Some, however, stayed to listen. As a result, Gittings and Kameny the following year staffed the first gay-positive booth ever to appear at an APA meeting. The exhibit, “Gay, Proud and Healthy: The Homosexual Community Speaks,” included pho-

⁶². Franklin E. Kameny, telephone interview with author, 27 March 1993.

⁶³. Barbara Gittings, telephone interview with author, 8 April 1993.

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tos of happy lesbians and gay men—a novelty for most of the psychiatrists who stopped by the booth.

“In the spirit of the times,” as he put it, Kameny and others also zapped an exhibition on “aversion therapy,” a meeting of Irving Bieber’s, and the APA’s prestigious Convocation of Fellows, where Kameny lambasted the assembled doctors as the incarnated enemy of gay people. The APA responded by inviting Kameny and Gittings to participate in the first APA panel ever to deal positively with homosexuality, during its 1972 annual meeting in Dallas.

When I spoke with him two decades later, John E. Fryer, MD was an openly gay professor of psychiatry at Temple University in Philadelphia. But in 1972, Fryer was so unnerved by Gittings’s invitation to appear on the panel in Dallas that he agreed only on condition that he be disguised and his amplified voice distorted beyond recognition.

In the panel, titled “Psychiatry: Friend or Foe to Homosexuals: A Dialogue,” “H. Anonymous, MD,” bedecked in a rubber mask, wig, and oversized tuxedo, debuted to an audience of about five hundred psychiatrists, recalled Fryer, laughing. At the time, however, he sadly lamented to his colleagues, “My greatest loss is my honest humanity. How incredible that we homosexual psychiatrists cannot be honest in a profession that calls itself compassionate and ‘helping.’”⁶⁴ The *Advocate* noted that the Dallas meeting might well have marked a “turning point” in the relationship between psychiatry and the gay community.

After reviewing the scientific literature and working closely with gay rights advocates, including Bruce Voeller, from the

⁶⁴. “Psychiatrists Blast Colleagues’ Prejudice Against Homosexuals,” *Psychiatric News* (7 June 1972), 6.

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newly formed National Gay Task Force, Robert Spitzer, a member of the APA's nomenclature committee, prepared a background paper on homosexuality for the APA's board of trustees. In it he defined the simple standard by which psychiatrists to this day gauge mental illness: For a psychiatric condition to be considered a mental illness, it must either cause distress or impair an individual's social functioning. "Clearly," wrote Spitzer, "homosexuality, per se, does not meet the requirements for a psychiatric disorder since...many homosexuals are quite satisfied with their sexual orientation and demonstrate no generalized impairment in social effectiveness or functioning." For the record, he noted, "the terms 'normal' and 'abnormal' are not really psychiatric terms."⁶⁵

The APA's board of trustees agreed with Spitzer's assessment, and voted unanimously in December 1973 to remove homosexuality from the *Diagnostic and Statistical Manual*. It acknowledged that "the unscientific inclusion of homosexuality per se in the list of mental disorders has been the ideological mainstay for denying civil rights" to homosexuals. As if to atone for the profession's many years of mistreating homosexuals, the board also called for the repeal of sodomy laws and for the passage of antidiscrimination measures to protect the rights of gay people."⁶⁶

Not all psychiatrists welcomed the change in diagnosis, chief among them Bieber and Socarides. Hoping to overturn the APA board's decision, the two demanded a referendum for the entire membership. Bieber regurgitated the traditional

⁶⁵. Robert L. Spitzer, M.D., "The Homosexuality Decision—A Background Paper," *Psychiatric News* (16 January 1974), 11.

⁶⁶. Charles Hite, "APA Rules Homosexuality Not Necessarily a Disorder," *Psychiatric News* (6 January 1974), 1.

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pathology argument in a statement in *Psychiatric News*, the APA's official newspaper. "Homosexuality," he wrote, "is always a consequence of a disordered sexual development, usually the outcome of a singular kind of disturbed network of relationships within a family."⁶⁷ Fifty-eight percent of the ten thousand psychiatrists who voted in the referendum upheld the board's decision.

To placate the traditionalists like Bieber and Socarides, the board created a new category of illness, "sexual orientation disturbance." In this obviously politically motivated classification, having a homosexual orientation was no longer a problem, but being unhappy to the point of wishing to be heterosexual was. Content to leave well enough alone, at least for the time being, even gay activists mostly ignored the so-called "ego-dystonic homosexuality." As Kameny was wont to say at the time, "Anyone who is unhappy being gay must be crazy!"

In 1986, the APA finally deleted even "ego-dystonic homosexuality" from the diagnostic manual, removing the last official medical impediment to homosexuality's being considered a normal and healthy variant of human sexuality. The fear and loathing of gay people—dubbed "homophobia" by George Weinburg in his 1972 book, *Society and the Healthy Homosexual*—was finally seen as the root cause of the psychic stress from which so many gay people suffered.

When he started writing for the gay press in the late seventies, New York physician Lawrence D. (Larry) Mass said he was "fascinated with this business of what is homosexuality, how it's

⁶⁷. Irving Bieber, "Against Trustees' Action: A Statement by Irving Bieber," *Psychiatric News* (6 February 1974), 1.

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defined, where we stand scientifically.”⁶⁸ Mass was particularly interested in psychiatry. In fact, after already practicing medicine, Mass at one point wanted to retrain as a psychiatrist but was rejected from several psychiatric residency programs because he was honest about his sexual orientation when asked. His own therapist while in medical school had been none other than Richard Pillard, the first psychiatrist in America to reveal himself publicly as a gay man.

Mass saw himself as a kind of “watchdog of psychiatry,” keeping up with developments in the field and duly reporting them in the gay press. Given his awareness of the tepid acceptance by many psychiatrists of the APA’s decision to declassify homosexuality, Mass continually worried that psychiatry would find a way to return it to the list of mental illnesses. In particular, Mass feared that the promiscuity and STDs so rampant among urban gay men in the seventies could be just the thing the APA needed to declare that homosexuals really are pathological after all.

By the time AIDS appeared, Mass was an established medical writer in the gay press, and had sharpened his critique of the medical establishment’s history as the enforcer of society’s wish to “control” homosexuality. Mass’s well-informed views of both medicine and gay culture and politics, and a skepticism toward the medical establishment based on his own experience with psychiatry, would prove invaluable in the early years of the epidemic as thousands of gay people throughout the country depended upon his medical articles for the earliest news about the AIDS epidemic.

⁶⁸. Lawrence D. Mass, MD Interview with author, New York City, 28 April 1995.

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Like all medical doctors, psychiatrists had enjoyed a level of power and authority in American society accorded them because, at least to nonscientists, they seemed to hold the keys to the mysteries of human life. They were frequently likened to priests, and certainly their views were considered sacrosanct to the many who depended upon authorities to define for them what is right and wrong.

It took enormous audacity and bravery for gay men and lesbians to stand up for themselves against the psychiatric profession. Howard Brown, MD, formerly director of public health for New York City before he came out publicly as a gay man in 1973, noted in *Familiar Faces, Hidden Lives*, “The gay activists who converged on Washington on December 15, 1973, were the first group of patients in history to insist that they were not sick and to demand that the label be removed.” When the APA agreed and voted to depathologize homosexuality, wrote Brown, “Never in history had so many people been cured in so little time.”⁶⁹

The willingness of gay people to stand up for themselves against the medical establishment in the 1970s would reverberate into the eighties and beyond, as they once again stood up to demand attention for a deadly new disease that made people squirm in discomfort because of its connections to sex and drug use. But discomfort was nothing compared to the devastation of AIDS, and it would be homosexuals once again who pushed the medical establishment and American society itself to overcome their prejudices, this time to save lives.

⁶⁹. Howard Brown, MD, *Familiar Faces, Hidden Lives: The Story of Homosexual Men in America Today* (New York: Harcourt Brace Jovanovich, 1976), 204, 201.

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Despite the shift in the American Psychiatric Association's position on homosexuality, "modern medicine," as it was often called with a note of awe, seemed unassailable in the seventies. The medical establishment was at the apex of a self-confidence tilting toward cockiness when it came to infectious diseases that had long plagued humanity. In the 1950s and 1960s, a number of deadly diseases were successfully treated and controlled, including polio, influenza, and tuberculosis.

By the end of the seventies, modern medicine could claim an astounding success in the complete eradication from the world of smallpox, an ancient scourge that had killed and disfigured millions. It was a time of great optimism that medicine would eventually solve every biological affliction of humankind. As Pulitzer Prize-winning medical reporter Laurie Garrett puts it, "Few scientists or physicians of the day doubted that humanity would continue on its linear course of triumphs over the microbes."⁷⁰

Nearly drowned in the din of self-congratulation were the importunate voices of medical experts warning that it was far too soon for a victory celebration. In 1981, Richard Krause, director of the National Institute of Allergy and Infectious Diseases, published a book called *The Restless Tide: The Persistent Challenge of the Microbial World*. Krause warned that diseases believed to have been defeated could return to endanger

⁷⁰. Laurie Garrett, *The Coming Plague: Newly Emerging Diseases in a World Out of Balance* (New York: Penguin Books, 1994), 30.

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the American people. The following year, Krause was asked in a congressional hearing why the country suffered from so many infectious diseases. He answered, “Nothing new has happened. Plagues are as certain as death and taxes.”⁷¹

Of course the appearance of a deadly new viral disease—sexually transmitted, no less—would shake up the medical establishment beginning the very year Krause’s book was published. As Mirko D. Grmek, former president of the International Academy of the History of Sciences, puts it, “The AIDS epidemic caught us unaware and aroused the return of irrational fears because it exposed the impotence of modern medicine just when we had begun to believe that the infectious diseases had been vanquished for good.”⁷²

Centuries before a minute retrovirus finally revealed the mortal limitations of the “all-powerful” Oz—like the wizard, “modern medicine” was seen as magical and all-powerful because of the wonderful things it did—the Puritanism of some of the nation’s earliest colonists was passed down through history to shape the peculiarly American attitude of shame and embarrassment about sex and sexually transmitted disease.

With a light touch, H. L. Mencken defined “Puritanism” as “the fear that someone somewhere is having a good time.” Far more often the deep-seated distrust of pleasure and bodily life underlying America’s collective sexual shame—even as its popular culture uses sexy bodies and the promise of “peak per-

⁷¹. Krause quoted in *Ibid.*, 5.

⁷². Mirko D. Grmek, MD, Ph.D. *History of AIDS: Emergence and Origin of a Modern Pandemic*. Translated by Russell C. Maulitz and Jacalyn Duffin (Princeton, NJ: Princeton University Press, 1990), 41.

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formance” to sell everything from toothpaste to automobiles—plays out in the darkness of denial. With such a schizoid attitude toward sex, can anyone be surprised that the U.S. has the highest rate of sexual diseases and teenage pregnancies in the developed world?⁷³

We insist on seeing sexual diseases as among the worst possible things that can happen to someone, or that an individual could give to another. STDs are regarded as a well-deserved “punishment” for daring to flout the norms to which most Americans adhere, even if their adherence is stronger in word than in deed. For men reveling in the sexual “freedom” of the urban gay ghettos, flouting social norms merely by being alive, the norm that condemned STDs as unspeakably shameful, was brushed aside along with the “middle-class values” that were so often derided as antiquated. As Frank Browning puts it in *The Culture of Desire*, “Born into a society whose medical establishment told them that because they were homosexual they were diseased, then let loose into the orgy of the bathhouse era, when gonorrhea was a minor inconvenience dispatched with a shot of penicillin, gay men who came of age in the days before AIDS have had good reason to see themselves as outsiders to the medical codes that most people live by.”⁷⁴

But gonorrhea was the tamest of the sexual bugs that gay men were passing around amongst themselves in the seven-

⁷³. Warren E. Leary, “U.S.’s Rate of Sexual Disease Is Highest in Developed World,” *New York Times* (20 November 1996), D20; Ethan Bronner, “No Sexology, Please. We’re Americans,” *New York Times* “Week in Review” (1 February 1998), 6.

⁷⁴. Frank Browning, *The Culture of Desire: Paradox and Perversity in Gay Lives Today* (New York: Crown Publishers, 1993), 113.

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ties. By 1980, studies were showing that 93 percent of sexually active urban gay men were infected with cytomegalovirus, a herpes virus that had been linked to cancer. Epstein-Barr virus, a microbe best known for its connection to mononucleosis (the “kissing disease”) but also linked to cancers, had become pandemic among gay men.⁷⁵ Because of the increased popularity of anal sex in the seventies, hepatitis B evolved from being a blood-borne pathogen into a sexually transmitted disease.⁷⁶ Amebiasis, the most serious sexual infection among gay men after hepatitis B and before AIDS, was casually referred to as “gay bowel syndrome.”

Like hepatitis B, amebiasis had not been a sexually transmitted infection prior to its getting into the “mix” of pathogens being transmitted regularly by and among gay men; it mainly afflicted poor people living in abject squalor in third world countries. Now it was challenging even modern medicine. Dr. Donna Mildvan, an authority on the disease, told Larry Mass in an interview, “The reason [amebiasis] has been so difficult to treat is that, often, it is not the only organism causing symptoms in gay males who have amebiasis. These patients may have giardia, shigella, or other enteric pathogens.”⁷⁷

Dennis Altman notes that in the “liberated” seventies, when promiscuity was seen as a virtue in some segments of the gay community, “being responsible about one’s health was equated with having frequent checks for syphilis and gonorrhea, and

⁷⁵. Shilts, *And the Band Played On*, 48.

⁷⁶. Ibid., 39.

⁷⁷. Lawrence D. Mass, MD, *Homosexuality and Sexuality: Dialogues of the Sexual Revolution*, vol. 1 (New York: Harrington Park Press, 1990), 133–34.

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such doubtful practices as taking a couple of tetracycline capsules before going to the baths.”⁷⁸

To gay men for whom sex was the center and circumference of their lives, their only real health concern was that illness would prevent them from having sex—which, to their way of thinking, meant they would no longer be “proudly” gay. Michael Callen recalled a lecture he attended on the eve of the AIDS epidemic in which Edmund White, who coauthored *The Joy of Gay Sex*, said that “gay men should wear their sexually transmitted diseases like red badges of courage in a war against a sex-negative society.” Said Callen, I remember nodding my head in vigorous agreement and saying to myself, ‘Gee! Every time I get the clap I’m striking a blow for the sexual revolution!’”⁷⁹

For Larry Mass, supporting the sexual revolution came naturally, though it required that he reconcile some unpleasant realities. While he believed that sexual and gender issues—including homosexuality, women’s rights, sex education, sexual freedom, birth control access, improvement of research and treatment of STDs—were “part of an interrelated package,” he also tried to understand the STD epidemics of the seventies in a larger context. “This meant pointing out that while gay people were having high rates of STDs, heterosexuals also were having epidemics of herpes and gonorrhea,” he said.⁸⁰

⁷⁸. Dennis Altman, *AIDS in the Mind of America* (New York: Anchor Press/Doubleday, 1986), 143.

⁷⁹. Callen, *Surviving AIDS*, 4.

⁸⁰. Mass interview.

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True as it was, the fact is that gay men accounted for vast majorities of the patients at many urban STD clinics. Pat Norman recalled that in San Francisco 85 percent of the people going to STD clinics in the seventies were gay men.⁸¹ And the number and types of infections gay men regularly contracted surprised even medical professionals.

When David Ostrow recruited Northwestern medical student Gary Remafedi in 1977 to help him provide STD screening in Chicago's bathhouses, the future pediatrician had no idea what awaited him. Ostrow took Remafedi, now a professor of pediatrics and noted expert on gay adolescents at the University of Minnesota in Minneapolis, to Man's Country, a Chicago bathhouse, and taught him how to draw blood. "I was astounded by what I was seeing," Remafedi told me. "It looked like everyone had warts or herpes. It was dreadful."⁸²

In 1978, *The Gay Health Guide* warned that "the mere fact that you are homosexually active exposes you to greater risk of VD than the person whose activity is exclusively heterosexual because your partner, if not also you yourself, is likely to have had more opportunities to contract a venereal disease." Written by New York urologist Robert L. Rowan and psychologist Paul Gillette, the guide delineated the sexual risks for gay men—and indeed they were manifold. The authors noted, "They range from the merely inconvenient, such as infestation of parasitic insects, to the severely limiting, such as fecal incontinence resulting from irreversible stretching of the anal sphincter muscle.

⁸¹. Norman interview.

⁸². Gary Remafedi, MD, telephone interview with author, 14 July 1995.

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They include, chiefly among males, rupture of the walls of the rectum and possibly fatal infection of the abdominal cavity.”⁸³

The guide certainly didn’t paint a picture of a sexually healthy community, to put it mildly. As Michael Callen described it, “Unwittingly, and with the best of revolutionary intentions, a small subset of gay men managed to create disease settings equivalent to those of poor third world nations in one of the richest nations on earth.”⁸⁴ In the late seventies, Selma Dritz, an infectious disease specialist for the San Francisco Department of Public Health, used to warn that “too much is being transmitted here.”⁸⁵

Urban gay American men were infected with disease-causing microbes that were previously considered problems only in poor, undeveloped areas of the world. After repeated bouts of these diseases, treatment with increasingly powerful antibiotics, and use of the recreational drugs that for many were just another “normal” part of ghetto life, the immune systems of many gay men were suppressed to dangerously low levels. As Ian Young puts it, “Years before AIDS, the health crisis of gay men could be seen daily in the lengthening lines at the VD clinics, the same men returning again and again.”⁸⁶

Where were gay doctors at the time? Why didn’t they take a leadership role in telling gay men to mind their health, possibly

⁸³. Robert L. Rowan, MD and Paul J. Gillette, PhD. *The Gay Health Guide: A Complete Medical Reference for Homosexually Active Men and Women* (Boston: Little, Brown, 1978), 3, 7.

⁸⁴. Callen, *Surviving AIDS*, 4.

⁸⁵. Shilts, *And the Band Played On*, 38.

⁸⁶. Young, *The Stonewall Experiment*, 166.

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even to use condoms to protect themselves against the range of microbes waiting to invade another warm body during sex? Dennis Altman says that most gay doctors were reluctant to warn their gay male patients about the negative consequences of repeated STDs lest they be dismissed as just another mouthpiece of the oppressive medical establishment.⁸⁷

Michael Callen recalled another reason for the doctors' silence. "Many of these physicians," he said, "could themselves be observed in the bathhouses and backrooms leading the same fast-lane lifestyle as their patients. Even if they had warned us, who would have listened?"⁸⁸

In some cities, gay physicians moonlighting as "clap doctors," as they were known in the community, were the first to provide "gay-sensitive" STD screening and treatment for gay men, often through an arrangement with a local bathhouse. In 1972, David Ostrow was approached by Horizons, a community social services organization in Chicago, where Ostrow was then a medical student, to offer testing and treatment one night a week. At the time, Ostrow recalled, "There weren't any gay doctors or others willing to hang out a shingle saying that they specialized in gay medicine. I know many gay doctors who were afraid that if they got known for seeing gay patients they were going to lose their straight patients." Ostrow said health authorities typically razzed gay men. "The biggest problem at the time with the Department of Health VD clinics," he said, "was that if you went in for anything other than penile discharge, and you asked for an oral or anal swab, they would go berserk—ask for names and numbers of every one of your sexual partners for the last ten years."

⁸⁷. Altman, *AIDS in the Mind of America*, 143.

⁸⁸. Callen, *Surviving AIDS*, 12.

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So Ostrow helped to start the Howard Brown Memorial Clinic (Howard Brown, the former New York City public health chief, died of heart disease in 1975), which—like the Fenway Community Health Center (today Fenway Health) in Boston, the Seattle Gay Clinic, and the Whitman-Walker Clinic in Washington, D.C.—started out as an alternative to public VD clinics, offering gay men something that, for many of them, was as important in their health care as their sex lives: anonymity.

In a move that would echo into the era of HIV antibody testing, Ostrow noted that it was in the early gay clinics that confidential STD testing was born. “We invented the system of using confidential codes of their initials or their mother’s maiden name and their birth date,” he said. Something else the gay clinics had in common was their shoestring budget. In Chicago, Ostrow recalled, “We met once a week above a grocery store across from the Biograph Theatre. Horizons had the coffee shop on one end of the room, and we had this set of curtains. I used to bring my kitchen table in and that’s what we would examine people on. And the medicines were whatever we could rip off of the clinics we worked or studied in.”⁸⁹

Individually, the clinics were sometimes hard-pressed to keep pace with the demand for their services. But when they joined other gay clinics across the country, the fledgling organizations discovered the advantages of networking and sharing information. In the mid-seventies, community-based STD clinics such as Howard Brown banded together with others throughout the country to form the National Coalition of Gay STD Services. Howard Brown was at the center of a nationwide network of

⁸⁹. David G. Ostrow, MD, interview with author, Chicago, 3 June 1995.

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agencies and individuals working with gay men in the area of STDs.

Ken Mayer, who worked with Ostrow at Howard Brown, while he was also a medical student in Chicago in the seventies, today is a professor at Brown University and medical research director at Fenway Health's Fenway Institute in Boston. He recalled the national STD coalition as "a bare-bones kind of organization—a mimeographed newsletter a couple times a year to let people know what others were doing."⁹⁰

Within a few years, largely as a result of this networking and keeping up with what others were doing around the country, a substantial national gay and lesbian health movement would emerge, providing an important cornerstone of the gay community's response to the AIDS epidemic. The gay clinics, together with gay men and lesbians in the health professions, would serve as invaluable sources of information, treatment, and community organizing. Said Mayer, "Particularly for gay men, it was fortunate for an emergency like AIDS that [the gay and lesbian health movement] was built around STDs."⁹¹

It was also fortunate for gay men that lesbians, steeped in the feminist politics of the late sixties and early seventies, understood the connection between personal health, the power dynamics of health care, and one's position in society. Lesbians also seemed to understand that gay liberation and gay rights were about vastly more than the "right" to be promiscuous. Many of these women had learned their own lessons about illness and health care by dealing not only with homophobic

⁹⁰. Kenneth Mayer, MD, interview with author, Boston, 25 July 1995.

⁹¹. Mayer interview.

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health care providers, but often with the public health system that was created in this country to provide basic services to those with lower income, a category that, unfortunately, includes many lesbians. Their political critique of the health care system arose from firsthand experience as both gay people and as women dealing with a system dominated by heterosexual men.

Of course there were gay men working in the health care professions, and it was through their joint efforts with lesbian colleagues that the gay and lesbian health movement was able both to create a momentum within the health care professions to consider the health of gay men and lesbians an issue worthy of serious attention.

Gay and lesbian health care professionals from a number of national organizations met in Philadelphia on May 30, 1976, where they formed the National Gay Health Coalition. According to Walter Lear, a key organizer of gay and lesbian members of the American Public Health Association (APHA), the coalition was created to provide gay health professionals with a means for sharing data and experience, and to facilitate relationships between the groups they formed within their national organizations and the community-level gay health services, community centers, political organizations, and periodicals.⁹²

From the day he walked down Thirteenth Street as a college student in Lawrence, Kansas, and saw a poster in a side window of a house that said, “Gay is Good—Stonewall,” Lawrence “Bopper” Deyton said he knew “there was something out there that would allow me to integrate my sexuality with something

⁹². Walter Lear, MD, “The National Gay Health Coalition,” *Lesbian & Gay Health* (Newsletter of the National Gay Health Education Foundation), January 1984.

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that was positive.” With a father and brother who were physicians, and a sister who was a nurse, Deyton seemed destined for a health career. But he also knew he wanted somehow to integrate his interest in the health field with his emerging gay political awareness.

Finally it came together while Deyton was in graduate school in Boston, earning a master’s degree in public health. “I met a boy in a bar and went home and had a wonderful time,” Deyton recalled. “He was a physical therapist and we talked about these issues. He said, ‘There’s this new group that’s forming in the APHA. I just got this flyer, and there’s this guy named Walter Lear and here’s his phone number.’ I called Walter the next day, and that’s how I got involved.”

For Deyton, Lear, and many other gay people in the health fields, the APHA’s willingness to embrace its gay members allowed the association’s gay and lesbian group to create what served as a model for gay people in other health organizations. Today Deyton is a medical doctor, former director of the AIDS research program at the National Institute of Allergy and Infectious Diseases (NIAID), and was named by President Barack Obama in 2009 to the newly created post of director of the Center for Tobacco Products within the Food and Drug Administration (FDA). While at NIAID, he explained in an interview that once a caucus of gay people came together within an organization—including social workers, nurses, medical students, psychologists, psychiatrists, and substance abuse workers—they emulated the APHA model, first organizing themselves, and then insisting upon integration with the larger organization. When AIDS appeared, he said, “There was a foundation—of

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relationships, of respect, of working together, of the gay and lesbian professionals in their organizations.”⁹³

In May 1978, two hundred men and women crowded into the basement of All Souls’ Unitarian Church, in Washington, D.C., for the first National Gay Health Conference, sponsored by the two-year-old National Gay Health Coalition. Dr. Paul Wiesner, from the federal Centers for Disease Control, delivered a keynote address about the “positive aspects and potentialities of the gay health movement.” The late Howard Brown’s sister, Jule Sibley, addressed the group before Walter Lear presented the first Jane Addams–Howard Brown Award for outstanding contributions to the health and welfare of the gay community—to none other than Evelyn Hooker, the psychologist who in the fifties revolutionized psychological research on homosexuals. The conference program notably reflected the fact that, six years after the American Psychiatric Association’s decision to declassify homosexuality, gay people working in the mental health fields had begun to address the societal homophobia now blamed for the high levels of psychic stress among many homosexuals.

The networks of gay health care professionals would prove to be vitally important in the gay community’s ability to mobilize services for people with AIDS and to mount a political response in Washington. But they were only part of the foundation laid in the seventies that would be built upon in the eighties as gay people were forced to address the AIDS epidemic. Equally important ties were established in the seventies between gay physicians, pharmaceutical companies, and government scientists when they collaborated in testing and, in 1978, licensing a vaccine to prevent hepatitis B.

⁹³. Lawrence “Bopper” Deyton, MD, interview with author, Rockville, Md., 24 September 1996.

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David Ostrow's medical specialty in gay health was strengthened when Ortho Pharmaceuticals approached Howard Brown about participating in a test of hepatitis B immune globulin. "They'd heard we had a clinic in Chicago seeing a lot of men with hepatitis," he recalled, "and they figured that gay men recovering from acute hepatitis would be ideal sources for the antibodies" they needed for their vaccine.

Ortho thus became the first drug company willing to work with a gay clinic in the US. The gay men seen at the clinic certainly were well-suited to the research: Ostrow said that not only did 10 percent of his patients have chronic hepatitis, but upwards of 60 percent of them had the actual disease at one time or another.⁹⁴

In San Francisco, gay men were recruited at the bathhouses for the hepatitis B studies. Some sixty-eight hundred blood samples were taken in the city in 1978, and stored for possible use in the future. Of course no one knew at the time that a few years later, hepatitis B would seem like the common cold in comparison to the lethal STD about to appear. By the time it did so, scientists like Donald Francis, with the Centers for Disease Control, would already have had years of experience working with gay men around hepatitis B and other STDs. As Francis told me, "We were already studying diseases of gay men, which made a huge difference in terms of the federal government's having at least some communication and inroad to the gay community. We had long-term close relationships following literally tens of thousands of gay men."⁹⁵

⁹⁴. Ostrow interview.

⁹⁵. Donald P. Francis, MD, Ph.D., interview with author, Washington, DC, 9 February 1995.

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The hepatitis B studies also would prove to have enormous importance in tracking the early spread of HIV. When an HIV antibody test finally became available, in 1985, Don Francis went back to the San Francisco blood samples he'd taken for the hepatitis B trials in 1978 and 1980. Of the 110 samples from 1978 that he tested, only one was positive. But 25 percent of the fifty samples from 1980 that he tested were infected with HIV. It seemed apparent that HIV had appeared among gay men in the city in the late seventies and spread rapidly.

Through the hepatitis B studies, gay physicians developed rapport and credibility with the government researchers—and vice versa. As Ken Mayer explained, “It was the first partnering of the government and gay community, and it created a cadre of health professionals who were considered responsible leaders in the gay community around health issues, and a certain amount of trust and bridge building.”⁹⁶

The working relationships between gay doctors and government scientists would prove mutually beneficial in the coming years, providing researchers with at least a basic understanding of gay sexuality and access to community leaders, and would offer the gay community a link to emerging scientific information about AIDS. These relationships would contribute significantly to bringing gay people into the “mainstream” of medical research. Clearly there had been some progress since the medical establishment viewed gay people as abnormal and mentally ill merely for being homosexual. Too bad it would have to take a deadly epidemic to bring them together.

As the silent killer made its insidious way among unsuspecting gay men, the doctors and scientists focused their attention

⁹⁶. Mayer interview.

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on the health crisis that was already building in the urban gay ghettos by the late seventies.

At a 1979 meeting in Chicago to celebrate the success of the hepatitis B vaccine, David Ostrow recalled Dr. James Curran, then head of the CDC's VD division and soon to become director of its AIDS program, telling the group, "If you people who represent the gay clinics in America think the vaccine is the answer to your problems, you're making a big mistake. If hepatitis B can go from *not* being an STD to *being* an STD because of behavior in the gay community, what *else* can do the same thing?" Then Curran warned the gay doctors of the possible social consequences. "If you as the gay community's health leaders don't clean up its act, sooner or later the health care problems will get such that they're such a threat to the larger community that they will force behavior change on the gay community."⁹⁷

Before that happened, a rash of bizarre illnesses and brutal deaths among young homosexuals in the nation's large coastal cities would perplex physicians and frighten gay men into making changes of their own. In a few short years, the seventies would be rued as a decade of abundant opportunities for sex—and bungled opportunities for making changes that would have saved lives. They were a decade when liberation wavered in an uneasy balance with oppression, as gay people struggled to define themselves on their own terms. Gay thinkers like Larry Kramer, gay doctors like David Ostrow, and government scientists like Jim Curran—people with sufficient perspective to see causal relationships where others saw only individual STD cases and isolated events—warned of dire consequences, if gay men didn't finally liberate themselves from an oppression they had turned in upon themselves.

⁹⁷. Ostrow interview.

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Like most prophets whose warnings disturb and alarm, the good counsel these people offered was mostly ignored. But the cost of ignoring a prophet has historically been high. Not even our latter-day prophets could have predicted just how high the cost would be this time.

PART 2

A POX ON OUR HOUSE

Love casts out fear, but conversely fear casts out love.

ALDOUS HUXLEY, *APE AND ESSENCE*

When young men in the gay ghettos suddenly began to die of rare and bizarre diseases, theories about the cause abounded. Scientists tried to figure out why gay men seemed to be singled out by the apparently new and extremely deadly scourge. Gay men looked everywhere for an explanation—except at their own behavior. They were desperate. The first people to die of AIDS were no different than themselves. Would they meet a similar fate? Straight people also recognized that gay men were just like them—except for that part about loving other men. This not only challenged their stereotypes and bigotry but meant that they could “catch it” too.

As if fear alone wasn’t challenging enough, those in the suddenly energized so-called Christian right—emboldened by their access to the highest levels of government—jumped on AIDS as if it was manna from heaven. They thrived on the fear and hatred of gay people that, for them, seemed a justifiable exception to Jesus’ commands to love others and to care for the sick. Even mainstream Americans took part. News that the agent causing AIDS was transmitted in blood products provoked a level of irrationality and scapegoating in the general

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public that was indistinguishable from the rantings of religious rightists.

Many gay men dug in their heels against the hysteria—and warnings within the gay community itself—refusing to yield one inch of what they viewed as their “freedom.” Community leaders were verbally flayed for daring to suggest that perhaps gay liberation and sexual license had been conflated once too often. Newly formed AIDS organizations hesitated to tell gay men “how” to have sex in ways that might save their lives lest they, too, be dismissed as homophobic and puritanical. Many in the fast lane wouldn’t or even couldn’t slow down, addicted as they were to sex, drugs, and the rush of finally being accepted by others. Unlike Andrew Holleran’s “prisoner of love” Mallone, though, the “sentence” for too many of these men was vastly more permanent than a broken heart.

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n 1979, Donald Abrams was doing his medical residency in San Francisco, when gay men began coming into the clinic where he worked, complaining of swollen glands. A hematologist friend at the clinic suggested that Abrams biopsy the lymph nodes to see what was going on. They were “reactive,” meaning that the men’s immune systems were overcharged as though fighting off some kind of infection. Abrams recalled, “We advised people to slow down. This was at the end of the seventies in San Francisco, and gay men had many partners, did drugs, and had a lot of STDs. We told patients to shift out of the fast lane for a while to see if their lymph nodes went down.” Looking back over the years and the more than half a million American AIDS cases that had been reported up to the time of our 1995 interview, Abrams added, “Retrospectively, that was one of our earliest indications that something was amiss.”⁹⁸

Everyone was puzzled by the deaths of the formerly healthy—though many had already been through repeated bouts of sexually transmitted infection and treatment—young gay men who were showing up with the unusually swollen lymph nodes, malaise, weight loss, fevers, thrush, rare tumors, and bizarre infections that would come to be associated with AIDS. The initial cases were thought to be isolated to New York and California, with no apparent link to one another. They were regarded as medical quirks signifying nothing. Some of the men had the purple lesions of Kaposi’s sarcoma, a rare skin cancer that

⁹⁸. Donald I. Abrams, MD, telephone interview with author, 17 July 1995.

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mainly afflicted older men of Jewish, Italian, or Ugandan extraction.

The federal Centers for Disease Control (CDC), in Atlanta, became aware of the unusual cases of *pneumocystis carinii* pneumonia that were afflicting other young men when the centers received multiple requests in the spring of 1981 for pentamidine, the standard drug to treat the disease that was ordinarily found among the elderly, transplant patients, or others with weakened immune systems.

The CDC's first report on the AIDS epidemic was published on page two of the June 5, 1981, issue of its *Morbidity and Mortality Weekly Report (MMWR)*. The report, titled "*Pneumocystis pneumonia—Los Angeles*," described the cases in five gay men being treated by Drs. Michael Gottlieb and Joel Weisman, in Los Angeles. In the mainstream press, only the *Los Angeles Times* carried the Associated Press story on the *MMWR* report. But the gay press already was setting the pace for reporting on AIDS.

Larry Mass was the first to note the AIDS epidemic. His reports in the *New York Native* were to become the gay community's earliest and best source of information in the epidemic's earliest years, as they were reprinted and circulated in gay newspapers throughout the country. In the May 18, 1981, issue of the *Native*—predating even the first CDC report—Mass wrote a news item about the "rumors that an exotic new disease had hit the gay community in New York."⁹⁹

⁹⁹. Edward Alwood, *Straight News: Gays, Lesbians, and the News Media* (New York: Columbia University Press, 1996), 212.

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At first no one saw a relationship between the odd cases of KS and PCP, as the skin cancer and pneumonia respectively would become commonly known when they became all too familiar. But in a July 3, 1981, letter in the *MMWR*, Dr. Alvin Friedman-Kien, a professor of dermatology and microbiology at New York University Medical Center, drew the connection between the cases of KS and PCP in New York City and California. His report, "Kaposi's Sarcoma and *Pneumocystis* Pneumonia Among Homosexual Men in New York City and California," also announced the appearance of another ten cases of PCP among gay men, including six in the San Francisco Bay area.

Donald Abrams heard a news report about the strange outbreak among gay men on the car radio as he drove to the airport for a flight to Seattle, where he was about to start a year-long fellowship in oncology. His experience with cancer would serve him well in the years ahead.

Friedman-Kien's report in the *MMWR* also attracted the attention of Dr. Lawrence K. Altman, a former CDC staffer who was now a medical writer for the *New York Times*. Buried on page A20, Altman's fairly brief July 3 news article represented the first mention among "all the news that's fit to print" of a disease that, within two years, would be called the most serious health threat of the century.

The article, "Rare Cancer Seen in 41 Homosexuals," was a tragic postscript to the gay pride celebrations of the previous week. In one of the crueler ironies of the AIDS epidemic, the date of the article's publication was precisely twelve years to the day after the first mainstream news report about the importance of the Stonewall rebellion to the budding gay liberation

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movement.¹⁰⁰ For many gay men, this July 3, 1981, date would forever mark the line between innocence and experience—the exuberant innocence of gay life before AIDS, and the doleful experience of so many gay deaths because of AIDS.

Once the link was made between the PCP and KS cases that had appeared on both coasts, bigger questions presented themselves: What was causing these diseases? Why were gay men being singled out among the population? And, above all else, why now?

No one knew the answers, although everyone had their own theories. In an interview with Friedman-Kien for the *Native*, Larry Mass asked the question that would baffle scientists for some time to come: “Why should immunosuppression be such a prominent feature in these cases?” The cases of KS and PCP were being referred to variously as Gay Related Immune Deficiency (GRID), Kaposi’s Sarcoma and Opportunistic Infections (KSOI), and Acquired Immunodeficiency (AID).

Friedman-Kien suggested a few possible reasons, including multiple sex partners, a history of numerous sexually transmitted diseases, and “poppers.” One of the strongest candidates seemed to be cytomegalovirus, a member of the herpes virus family known to suppress immunity, which was far more prevalent in sexually active gay men than in heterosexuals.¹⁰¹

¹⁰⁰. Ibid. The first mainstream news account to view the Stonewall rebellion as a major step forward in the gay liberation movement was a cover story by Lucian Truscott IV, in the *Village Voice* on 3 July 1969.

¹⁰¹. Lawrence D. Mass, MD, “Cancer in the Gay Community,” *New York Native* (27 July 1981), 1.

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In “Cancer in the Gay Community,” the first feature article ever written about AIDS, Mass described the consternation among medical observers of the early cases of KS and PCP among gay men. “Perhaps,” he wrote, “certain homosexuals in certain urban areas have been breathing, eating, drinking, or wearing unusual things, behaving in unusual ways, or frequenting unusual locations.”

He went on to add, more presciently than he realized at the time, “The most immediately seductive environmental explanation of ‘the gay cancer’ is that it is being caused by an infectious or otherwise cancerous agent. Because of their community proximity and physical interaction, perhaps some homosexuals are transmitting a carcinogen, a virus, parasite, bacteria, or other microbe.”¹⁰²

There were other “candidate etiologies” as well. Certain sexual practices that injured the rectum, particularly “fisting”—even sperm itself—were implicated as possible causes. Because only homosexuals seemed to be affected, conspiracy theories abounded. Perhaps, went one theory, an agent of chemical warfare had been loosed upon “undesirables” in a diabolical government experiment. Among the more far-fetched notions was Dennis Altman’s particular favorite: some sort of chemical agent “sprinkled like fairy dust on the floors of bathhouses where barefoot homosexuals would absorb it through their skin.”¹⁰³ As Mass subsequently, and not entirely facetiously, noted, “On the superficial basis of numbers alone, of course,

¹⁰². Ibid.

¹⁰³. Dennis Altman, *AIDS in the Mind of America* (Garden City, NY: Anchor Press/Doubleday, 1986), 43.

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wearing handkerchiefed Levi's and having Judy Garland records in one's collection might also seem risky."¹⁰⁴

One respected theory to explain the apparent selectivity of the disease was that some individuals were unusually susceptible to whatever it was that caused it. STD expert Donna Mildvan, chief of the infectious diseases division at New York's Beth Israel Medical Center, said, "There could be a genetic predisposition or some other vulnerability among selected individuals."¹⁰⁵

Chief among the more serious theories was the view that some kind of overload, caused by too many drugs and too many STDs, had resulted in an immunological meltdown that left fast-lane homosexuals prey to the variety of bizarre infections associated with AIDS. Dr. Joseph Sonnabend, a physician with a large gay practice in Greenwich Village, became the leading proponent of this theory.

"It seemed absolutely reasonable" to theorize a multifactorial cause for this new immune deficiency, Sonnabend told me in 2010. He pointed out that traditional understandings of disease posit that, even if there is an infectious agent involved, a variety of factors—among them genetics, diet, and other infections—contribute to how the disease will manifest itself and what course it will take in any given individual. Sonnabend said it also made sense, even early on, to believe whatever was causing "it" was related to sex—particularly receptive anal inter-

¹⁰⁴. Lawrence D. Mass, MD, "The Epidemic Continues: Facing a New Case Every Day, Researchers Are Still Bewildered," *New York Native* (29 March 1982), 1.

¹⁰⁵. Mass, "Cancer in the Gay Community."

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course. “I knew who was getting infected,” he said, “guys who were getting fucked.”

But there was little interest among the gay men organizing the earliest community responses in linking the new disease with an act that even recently liberated men might not want to speak of openly. There was even less interest in acknowledging publicly that many men were engaging in the act with many other men. Sonnabend said that “crazy macho bullshit” kept men from admitting they got fucked, and prevented them from learning sooner how to protect themselves.

As for the “absolutely vehement” hostility toward his multifactorial theory, he said, “the part that seemed to cause so much distress was talk about lifestyle.” Long before HIV was discovered, he said the single “killer virus” theory appealed to gay men who wanted, as he did, to remain positive about sex, but also wished for something that deflected attention from gay men’s behavior and “absolved promiscuity.”¹⁰⁶

In an editorial that accompanied the first articles on AIDS ever published in an American medical journal, David T. Durack, writing in the *New England Journal of Medicine* on December 10, 1981, asked, “Why this group? Why now, and not before?” He noted that homosexuality was nothing new, and wondered, “Were the homosexual contemporaries of Plato, Michelangelo, and Oscar Wilde subject to the risks of dying from opportunistic infections?” Of course a few deaths caused by unusual microbes could have passed unnoticed among the billions of deaths predating modern microbiology. But what of recent times? *Pneumocystis* had been known for almost thirty years and was fairly easy to identify. “Present indications,” con-

¹⁰⁶. Joseph Sonnabend, MD, telephone interview with author, 27 July 2010.

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cluded Durack, “are that we are seeing a truly new syndrome, not explainable by failure to diagnose earlier cases.”¹⁰⁷

Pulitzer Prize-winning medical reporter Laurie Garrett notes that, “The emergence and spread of HIV were ideal in the gay communities of the late 1970s in the US and Europe, particularly because the population was highly mobile and extraordinarily sexually active.” But something unusual must have happened that allowed a formerly obscure pathogen to suddenly find its way into America’s gay communities.

In fact, several things did happen. “Between 1970 and 1975,” says Garrett, “the world offered HIV an awesome list of amplification opportunities.” Among them were increased multiple partner sexual activity among gay men in North America and Europe and among urban heterosexuals in Africa; needles that were constantly reused in Africa because of shortages; soaring heroin, amphetamine, and cocaine use in the industrialized world; STD epidemics that lowered immunity and made the genitals and anus susceptible to HIV infection; and the burgeoning blood market.¹⁰⁸

The immune overload theory appealed to gay men who didn’t run in the fast lane, take drugs, or have multiple partners, because they could comfort themselves with a belief that only selected homosexuals would get the disease. “It’s only the ‘clones,’” they’d say, reassuring themselves that they had noth-

¹⁰⁷. David T. Durack, “Opportunistic Infections and Kaposi’s Sarcoma in Homosexual Men,” *New England Journal of Medicine* 305 (1981): 1465–67.

¹⁰⁸. Laurie Garrett, *The Coming Plague: Newly Emerging Diseases in a World Out of Balance* (New York: Penguin Books, 1994), 389.

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ing to worry about because they were “good” gays who only did one drug at a time, or were monogamous, or lived outside the early AIDS epicenters of New York, San Francisco, and Los Angeles. These men could hear the testimonials of early AIDS patients and not find any relevance to their own lives. But then, even some of those early patients were surprised to be diagnosed with AIDS because they didn’t see themselves as fitting what already had become the stereotype of a “typical” person with AIDS.

In the first mainstream magazine article about AIDS anywhere (“The Gay Plague,” it was called), *New York* in May 1982 quoted the CDC’s special Task Force on Kaposi’s Sarcoma and Opportunistic Infections, headed by Jim Curran, in describing the “average AID victim.” According to the task force, the individual—always a gay man, as those not fitting the “average” were simply not described—“is thirty-five years old, has a college degree, and makes between \$20,000 and \$25,000 a year. He is likely to be white, to have grown up outside New York City and migrated here somewhere between ten and fifteen years ago. He had been relatively healthy and always employed. He had led vigorous work and social lives—until about six months to a year before his diagnosis.”¹⁰⁹

Mark Wood, a gay man in San Francisco whose partner, Bobby Reynolds, was one of the city’s earliest and best-known AIDS patients, was as surprised as anyone by his diagnosis. When asked what he thought about his own risk for AIDS at the time of his lover’s diagnosis the previous year, Wood said, “Almost nonexistent. I never, at that point, thought that it would be the remotest possibility.” He didn’t live a fast life and do lots of drugs and have multiple sex partners and kinky sex—the things

¹⁰⁹. Michael Ver Meulen, “The Gay Plague,” *New York* (31 May 1982), 54.

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he was led to believe would endanger him. "I didn't fit any of those criteria," said Wood. "I'd always been real healthy. I'd never had any lengthy illnesses other than the standard gay diseases of VD and some strep throat, but never anything that had debilitated my body for any period of time."¹¹⁰

Larry Kramer, who had kept a low profile since the uproar over *Faggots*, used his name recognition to call attention to the new disease. In a "personal appeal" that ran alongside Mass's "Cancer" article in the *Native*, Kramer wrote, "The men who have been stricken don't appear to have done anything that many New York gay men haven't done at one time or another. We're appalled that this is happening to them and terrified that it could happen to us. It's easy to become frightened that one of the many things we've done or taken over the past years may be all that it takes for a cancer to grow from a tiny something or other, that got in there who knows when from doing who knows what."¹¹¹

At an April 8, 1982, dance benefit at the West Village's Paradise Garage for Gay Men's Health Crisis—the group that Kramer, Mass, and their friends formed to conduct research on AIDS, provide services to those with the disease, and educate others about it—GMHC's board president, Paul Popham, told the two thousand men and a few women who each had paid twenty dollars to attend the dance, "We are in the grip of a medical emergency. Something we have done to our bodies—and we still don't know what it is—has brought us close to death. The finest minds in medicine are on our side, but the

¹¹⁰. In Lon G. Nungesser, *Epidemic of Courage: Facing AIDS in America* (New York: St. Martin's Press, 1986), 136.

¹¹¹. Larry Kramer, "A Personal Appeal from Larry Kramer," *New York Native* (24 August 1981).

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problem is ours. The threat to our confidence is enormous...We've got to show the outside world that we've got more than looks, brains, talent, and money. We've got guts too, and lots of heart."

New York magazine reported, "At the Paradise benefit, a saucy three-woman disco ensemble called the Ritchie Family closed its set with some motherly advice, counseling the men to stay out of the bathhouses, out of the back rooms, 'and, this is the cardinal rule, fellas: one lover per person.' The audience formed its own impromptu chorus, chanting back, 'NO WAY!' Everyone enjoyed a healthy laugh. It was, however, a laugh informed with fear."¹¹²

The fear would become palpable as the protective, often self-righteous, bubbles in which many gay men lived were burst within a year after the first reports of AIDS.

By June 1982, CDC researchers had uncovered evidence to link GRID cases through a network of sexual relationships among forty gay men in ten different cities, including New York, Atlanta, Houston, Miami, San Francisco, and Los Angeles. The so-called Los Angeles Cluster Study offered powerful evidence that AIDS was not only transmissible—probably sexually—but that it was also likely to be the result of a single infectious agent. The study also offered clues about the seemingly long, asymptomatic latency period of the new disease.¹¹³ The Fire Island summerhouse of Paul Popham was the site of one of the first "clusters" of cases.

¹¹². See Ver Meulen, "The Gay Plague," 62.

¹¹³. Garrett, *The Coming Plague*, 306.

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What gay New Yorkers had taken to calling the “Saint’s disease,” because it seemed to afflict the men who frequented the popular disco called The Saint, suddenly became a disease of saints, sinners, and every other kind of homosexual—as well as growing numbers of heterosexuals. If, as was now suspected, AIDS was the result of sexual contact, any man who had ever had sex with another man was potentially at risk.

As of July 15, 1982, the CDC had received reports of 471 cases, and two new cases were being reported each day. The disease’s various names—which included a fourth, Acquired Community Immune Deficiency (ACID), CDC’s own name for it—were compressed into one dreaded and dreadful name by which the disease and the epidemic it spawned would be known, Acquired Immune Deficiency Syndrome, or “AIDS.”¹¹⁴

With the evidence linking AIDS to sexual contact, the many questions that had confounded everyone from the beginning now were distilled to a mere two. The answers to these two questions—and it is important to bear in mind that no one knew the answers—literally meant the difference between life and death: How can I avoid getting it? And the other, shattering in its implications: What if I already have it?

Hundreds of gay physicians met in San Francisco for the second annual Gay Pride Week symposium, called “Medical Aspects of Sexual Orientation,” at the end of June 1982. The meeting was sponsored by Bay Area Physicians for Human Rights (BAPHR), the oldest and largest organization of gay physicians in the country with 350 members at the time. The newly formed American Association of Physicians for Human Rights (AAPHR, today known as the Gay and Lesbian Medical

¹¹⁴. Randy Shilts, *And the Band Played On* (New York: St. Martin’s Press, 1987), 147, 149, 171.

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Association) held its first major membership drive during the symposium. Issues related to STDs and AIDS accounted for less than a quarter of the program.

Foremost among the physicians' STD-related concerns was the prediction of "a disastrous new gay cancer in the 1980s and nineties as a result of the increased incidence of hepatitis B in the 1960s and seventies." Those who become chronic carriers of the hepatitis B virus—upwards of 10 percent of infected individuals—have a high risk of developing liver cancer or cirrhosis (scarring).

Dr. Patrick McGraw, cofounder and president of the Resource Foundation, a community organization committed to ending the epidemic of hepatitis B, said, "Unless we can use the immunization techniques that are now available to curtail the epidemic of [hepatitis B] virus, [gay men] will probably always have an unfortunate prevalence of this highly fatal carcinoma."

Reporting on the symposium for the *Native*, Larry Mass noted, "Both BAPHR and AAPHR are anticipating the forthcoming hepatitis B vaccine crisis. At \$150 a shot, many of the young, sexually active gay men who would most benefit themselves and others from immunization, will not be able to pay for it." As though he could see ahead to what would happen in the AIDS epidemic in the coming years, Mass added, "As has so often been the case for important gay health care services, the money will have to be raised by the gay community."

As the gay doctors marched in San Francisco's annual Gay and Lesbian Freedom Day Parade, they saw members of the roller-skating Sisters of Perpetual Indulgence—a group of campy gay men dressed as nuns—handing out a leaflet called "Play Fair!" The sisters, many of whom were themselves health

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care professionals in “real” life, used whimsical language in this first attempt to define “safe sex” for gay men. “Don’t put other people at risk by engaging in sexual activity,” warned the leaflet. “Wait until you KNOW you can cum clean.”

Echoing the advice of the Committee to Monitor Poppers, which was formed in 1981 by San Francisco gay activist Hank Wilson when the nitrites were first implicated as a possible cause of AIDS,¹¹⁵ the sisters warned, “The Reverend Mother has determined that popper inhalation may be dangerous to your health.”¹¹⁶

Gay leaders met in New York on July 12 with Jim Curran, who traveled from Atlanta to brief the group on the AID (it was not yet called AIDS) situation, particularly the recent discovery of cases among nongay hemophiliacs. According to the National Gay Task Force executive director Lucia Valeska, “Curran emphasized his feeling that leading gay organizations and individuals must become directly involved in the government’s public information efforts on AID as well as in the formation of public policy for combating it.”

Valeska noted that Curran’s request that the gay community formulate an “appropriate” response had thrown the group of leaders into a quandary. How, they asked, can you determine what is an “appropriate” response to a disease for which neither the cause nor cure is known? And because the political context

¹¹⁵. Hank Wilson, interview with author, San Francisco, 30 January 1995.

¹¹⁶. All direct quotations about the BAPHR symposium are borrowed from Lawrence D. Mass, MD, “Creative Sex, Creative Medicine: Gay Physicians Meet for a Health Conference,” *New York Native* (19 July 1982), 11, 13.

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of the new disease was “extremely tricky and volatile,” as Valeska put it, any recommendations the leaders might make were likely to be interpreted in some quarters as “serving some special interest.”

As the task force prepared to host the first national forum on AIDS, to be held during the annual gay and lesbian health conference in Dallas that August, Assistant Secretary for Health Dr. Edward N. Brandt called for another meeting later that month. The task force put the gay community’s best foot forward, sending “scientifically credible” gay community representatives—Dr. Roger Enlow, a respected immunologist, and Bruce Voeller, who held a doctorate in biology and was a savvy politico. Valeska noted that this meeting marked the first formal relationship between the gay community and the federal government in the eighteen months of the new Reagan administration

Going into the meeting, community leaders were concerned about the political ramifications of the new disease so disproportionately affecting gay men. As Valeska put it, “What if the disease is infectious and traveling from the gay community outward? We have to make decisions in the dark, but how we respond may have grave implications for our political as well as medical welfare.”¹¹⁷

Larry Mass, Roger Enlow, and Dan William were invited as openly gay physicians to give presentations at the first international workshop on AIDS, held at Mount Sinai Medical Center in New York, on July 13, 1982. After noting that only a virus “would seem able to provide a unitary hypothesis that could explain the sudden appearance of AID in a growing num-

¹¹⁷. Lucia Valeska, “AID: The Appropriate Response.” *Task Force Report* (Newsletter of the National Gay Task Force) 9 (August/September 1982).

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ber of distinctive populations,” Mass voiced what he believed was an obvious and sensible cornerstone for any kind of prevention strategy that might be devised to prevent AIDS. He reasoned that instead of forcing gay people into a Catch-22 by condemning them for having gay relationships—making them “sexual outlaws, as John Rechy put it—society should provide homosexuals with the legal, theological, and social opportunities to establish committed love relationships.

Hoping others would see the reasonableness of his view, Mass concluded his remarks at the workshop by saying, “The passage of civil rights legislation for gay people will begin to be seen as a critical cofactor in the preventive medicine of sexually transmitted diseases, which probably include AID.”¹¹⁸

Seeking to quell the rising fears of gay men, and to quash the homophobic backlash that gay leaders expected would be stirred up by the growing epidemic, Mass’s copresenter Dan William told Mass in a *Native* interview, “What needs to be emphasized is that homosexuality per se is not a risk factor.” William, a gay New York City internist specializing in STDs among gay men, foreshadowed two volatile issues that would take on lives of their own in the coming years: bathhouses and blood donations.

Noting that a significant portion of gay men with AIDS had visited bathhouses prior to developing the disease, William observed, “Restaurants are now required to post signs describing the Heimlich Maneuver, a simple, easily learned technique for saving the life of someone who is choking on food. Perhaps baths should post signs that warn their customers of health risks and advise them about precautionary measures.” As for

¹¹⁸. Lawrence D. Mass, MD, “A Major Meeting on the Epidemic,” *New York Native* (2 August 1982).

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blood transfusions, William said, “I think I would advise promiscuous gay men with a prior history of multiple sexually transmitted diseases not to give blood until more information is available.”¹¹⁹

Lesbian activist Ginny Apuzzo, then the director of the Fund for Human Dignity, an affiliate of NGTF, had warned at the July 13 workshop that, like other minorities that had been scapegoated, gay men risked being further stigmatized for having “bad blood” if they were singled out for exclusion for blood donations. But gay men were already stigmatized because of the perception—this was three years before an antibody test afforded the ability to know who did or did not have the mysterious pathogen lurking in their bloodstream—that every one of them was tainted by whatever “it” was causing AIDS.

Despite the appearance of the disease in nongay people (besides homosexuals, the other three of the so-called “Four H” group believed to carry special risk were hemophiliacs, Haitians, and heroin injectors), the view that AIDS was a “gay disease” meant these others were discounted at first as simply unfortunate anomalies.

Astonishingly, even scientists thought they were dealing with a disease that somehow had a sexual orientation, extrapolating to a microbe the prejudiced belief of many heterosexuals that more than just sexual orientation distinguishes homosexuals from “normal” human beings, which is to say heterosexuals.

Researchers continued to look for something unique about gay men in their efforts to deduce the cause of AIDS. To be fair, we should note that one of the main reasons they focused on

¹¹⁹. Lawrence D. Mass, MD, “Time for Prevention: Devising Ways of Evading AID,” *New York Native* (16 August 1982), 31.

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gay men, rather than the others with AIDS, is that gay men demanded attention from medical care providers—and because a number of prominent gay leaders were themselves medical professionals.

In an early 1982 article he originally wrote for the *Village Voice* titled “The Most Important New Public Health Problem in the United States,” Larry Mass quoted Dr. Yehudi Felman, New York City’s foremost expert on STDs, as saying that other groups—he mentioned women (who suffered more frequently than most from gonorrhea and nongonococcal urethritis), Blacks, and Hispanics (both groups that had disproportionately high rates of some STDs)—hadn’t been as active as homosexuals in asking for better care because they didn’t want the stigma attached to having STDs. Gay men were different, though. Said Feldman, “Gays, who are used to stigma, are willing to fight for their needs.”¹²⁰

In 1982, the fight had just begun.

¹²⁰. Mass, “The Epidemic Continues.”

SIX

America's blood industry will be tainted forever by the way it shirked responsibility in the early years of the AIDS epidemic. Thousands of people were put at risk of contracting HIV—and thousands more actually did—because for several critical years after the appearance of AIDS among hemophiliacs and transfusion recipients, industry officials refused to acknowledge the probability that the nation's blood supply had been infected by the unknown pathogen believed to be causing AIDS. They refused to use tests available at the time that would have eliminated at least some of the infected blood. As early as July 1982, the CDC warned the blood industry of the problem and asked blood banks not to accept donations from gay men and injection drug users. It would be several years, and many transfusion-related infections later, before the industry finally listened.

In August 1982, the CDC recommended to the Public Health Service that all blood be tested for evidence of hepatitis B, using a test that measured for the virus itself, because there seemed to be a high correlation between symptoms of AIDS and the bloodborne hepatitis B commonly found among gay men and needle users. In December 1982, the first fully documented case of AIDS from a blood transfusion was reported, providing the strongest evidence to that point that the "it" causing AIDS was transmissible by blood as well as sex. Even so, the president of the New York Blood Center a month later de-

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nied the evidence that AIDS could be linked to a blood transfusion.¹²¹

While the CDC and blood industry officials wrangled over guidelines for blood donations, gay leaders were vehement that any policy which excluded all gay men would risk not only stigmatizing the would-be donors but might also have such serious consequences as getting them fired from their jobs. Ironically, these community leaders made their argument against a blanket exclusion by invoking the very same denial of widespread risk among gay men with which so many of them had deluded themselves into thinking they were safe.

Bruce Voeller, representing the National Gay Task Force at a meeting of CDC and blood industry officials on January 4, 1983, said, "So-called 'fast-lane' gays are causing the problem and they are just a minority of male homosexuals. You'll stigmatize, at the time of a major civil rights movement, a whole group, only a tiny fraction of whom qualify as the problem we are here to address."¹²²

CDC researcher Don Francis was generally sympathetic to the gay community's efforts to win civil rights. This time, though, he strongly disagreed with the gay leaders. While he understood their point about the risk of stigmatizing a whole group of people for the "sins" of the few, his commitment to ensuring the public health superseded politics of any kind.

¹²¹. Charles Perrow, Mauro F. Guillén, *The AIDS Disaster: The Failure of Organizations in New York and the Nation* (New Haven: Yale University Press, 1990), 38.

¹²². Shilts, *And the Band Played On*, 222.

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"I agreed with them that a monogamous or abstinent gay man who's never had sex is a perfectly fine blood donor," Francis recalled. "But short of that I wasn't willing to accept a gay man as a blood donor if he didn't know all his sexual partners—because I knew what the sexual activity of gay men was."¹²³ As Francis saw it, "there is no civil right to donate blood."¹²⁴

For gay people who too often felt their very humanity questioned, the "right" to donate blood had everything to do with the desire to be seen as human beings whose blood possessed the same lifegiving properties as that of nongay people. Gay men routinely participated in blood drives for the same humanitarian reasons as their heterosexual counterparts. Also like many heterosexuals, gay men often donated blood because of the same pressure to give that everyone else feels when, for example, there is an office blood drive.

Ginny Apuzzo, who argued against excluding gay men, recalled, "My concern was that gay men who were fearful of losing their jobs or suffering from other things could feel pressure to donate blood during some kind of community blood drive. If you asked them to abstain, you could be asking them to identify themselves as gay and then people would conclude that they had AIDS." Apuzzo and other gay leaders feared this unwitting "outing" of gay men might have real and dire consequences. As she said, "Look at what this country did to children with AIDS,

¹²³. Donald P. Francis, MD, PhD, interview with author, Washington, DC, 9 February 1995.

¹²⁴. Francis, telephone conversation with author, 24 January 1995.

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not letting them go to school. What the hell would they do to a gay man in an office?”¹²⁵

As usually happened in the early years of the epidemic, the first inclination of public health officials was to stop the spread of AIDS—no matter what. Gay leaders counterbalanced these otherwise laudable efforts to protect the public health by pointing out that the “what” in the AIDS epidemic might well be an insufferably high political price to be paid by an already despised minority.

Pat Norman, who at the time was coordinator of gay and lesbian health in San Francisco’s public health department, recalled, “The first reaction was ‘let’s identify them, let’s mark them and make sure everybody knows them’—without taking into consideration the political ramifications of actions such as people losing families, jobs, or homes if some confidential information was put out.”¹²⁶

But gay people who saw the potential threat to their homes, livelihoods, and their very lives, were not about to accept passively the pronouncements of a medical establishment they felt had long since abandoned them to fend medically for themselves. Fortunately, as often happened in the crucial political moments in the epidemic, individuals who had feet planted on both sides of the issue were able to intervene in a way that ultimately resulted in a fairly reasonable compromise. One such person was Dr. Peter Page.

¹²⁵. Virginia Apuzzo, telephone interview with author, 8 August 1995.

¹²⁶. Pat Norman, telephone interview with author, 12 September 1995.

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In 1983, Page, a gay man, was medical director for the American Red Cross blood bank program for Massachusetts and Maine, headquartered in Boston. The city of Boston at the time had the nation's first full-time liaison to the gay community, Brian McNaught, appointed by the mayor to serve as a bridge between his office and the community.

Unlike his counterparts in other cities, Page considered himself fortunate because he at least had an individual to call upon who had the confidence of both the political establishment and the gay community. Page's own gayness also was an asset. As he told me, "Feeling comfortable with gayness and gay people, I had zero reluctance in diving right in and talking with people to learn about [AIDS]." He noted that others in the blood-bank industry weren't quite so comfortable around gay people.

Although Page is gay and Don Francis is not, they agreed that the public health was the number-one priority. For the general American public, said Page, "When they're sick and need to be transfused, they don't need to worry about the safety of the blood supply. And wrong though it is, they just don't need to have to worry about getting blood from a gay man who donated blood."

Page met with McNaught, telling him that he was concerned that "promiscuous gay men probably shouldn't be blood donors." McNaught resisted. "Gay men are being picked on again," Page recalled McNaught saying to him. "It's not fair to discriminate."

McNaught invited Page to meet with the AIDS task force he had organized. Page told the group of community leaders and medical professionals that together they needed to figure out a way to get people who might be at risk of being infectious and

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asymptomatic not to donate blood. Page suggested that gay men should self-defer from donations. At first the group demurred. Said Page, “The committee was not happy to hear this. They didn’t believe it, they didn’t like it, and they accused me of all sorts of bad things—discrimination, unfairness, and blame.” By the end of the meeting, though, Page recalled, “Somebody said, ‘Now wait a minute, we ought to listen to this character, Page. Maybe there’s something there, and we don’t want to walk away from it. We don’t want to be blamed for causing more of the problem. Let’s think about how we can act responsibly.’”

Working with Page and the Red Cross, the task force agreed to design an insert to be included in a brochure called “What You Should Know About Donating Blood,” which would be given to all prospective donors. To the request for self-deferral by anyone who had ever had hepatitis, injected drugs, or traveled to a malarial area, was added the line “If you’re a man with anonymous or multiple sexual partners, please don’t donate.” This self-deferral seemed a reasonable way to eliminate a significant number of potentially infected donations.

“As it turns out,” said Page, “we found ways not to discriminate, but to base donor deferral upon objective descriptions of behaviors, which we fine-tuned and made more strict over the years. We made some people mad—but as we say, donating blood is not a right, it’s a privilege.”

The AIDS task force agreed to help educate Boston’s gay community about blood donations, so that at least those with known risk would be discouraged from donating. And the level-headed approach that had been worked out by a gay doctor in the blood industry and gay community leaders in Boston became a model for other regions as Page’s counterparts in blood

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banks in other parts of the country, particularly those in nonurban areas, called him for advice about what to do.¹²⁷

While leaders in Boston's gay community were recommending that gay men not donate blood—my own doctor in Boston told me in January 1982 that I, as a gay man, should no longer donate blood—a group of New York gay medical and political leaders formed the AIDS Network to formulate and disseminate guidelines to the community urging gay men who believed themselves at risk to refrain from donating blood.

The AIDS Network—which included Ginny Apuzzo, Roger Enlow, Larry Kramer, Larry Mass, and Dan William—issued a statement on January 17, 1983, supporting the testing of blood and blood products for agents such as hepatitis B, and self-screening by individual blood donors. It also acknowledged that mere questioning of donors was inadequate for safeguarding the blood supply, just as a policy excluding any group from blood donation would be ineffective and inappropriate.¹²⁸

In San Francisco, the Bay Area Physicians for Human Rights urged gay men to cooperate with blood banks in screening themselves out as blood donors. But the national group, AAPHR, opposed the elimination of gay men from blood donation—other than those “who think they may be at increased risk for AIDS.” Of course relying upon gay men to determine whether they were at “increased risk” was, in 1983, ineffective,

¹²⁷. Peter Page, MD, interview with author, Washington, DC, 2 October 1995.

¹²⁸. Lawrence D. Mass, MD, *Dialogues of the Sexual Revolution*, vol. 1, *Homosexuality and Sexuality* (New York: Harrington Park Press, 1990), 144, 152–53.

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as no one knew then how AIDS was caused or exactly how to prevent getting or transmitting it.

Gay activists in Washington, DC, persuaded the American Red Cross not to ask about sexual orientation per se in donor questionnaires. In fact, Frank Kameny advised gay men to lie if their local blood bank asked about sexual orientation.¹²⁹ At a time when homosexual relations were considered criminal acts in more than half the states, it was no small consideration to expect someone to answer “yes” to a question about private behavior that was considered illegal.

In March 1983, the Public Health Service recommended that donors from high-risk groups—all gay men and injection drug users were indiscriminately lumped into this category—voluntarily refrain from donating blood and plasma. In fairness, it must be acknowledged that no one at the time could know for certain whether a particular gay man or drug user had AIDS. The antibody test was two years in the future and there was no telling, other than by overt symptoms, who did or did not have whatever was causing AIDS.

But in an extremely negligent move, Red Cross and other blood industry officials continued for well over a year afterward to refuse the use of other tests that would have prevented at least some HIV infections. Even more egregiously, they continued to deny that there was any risk at all from blood or blood products despite the mounting number of AIDS cases among transfusion patients and hemophiliacs that were attributable to these very causes.

Beginning in 1984, heat inactivation was used to kill the virus in plasma products such as Factor VIII, which was used

¹²⁹. Shilts, *And the Band Played On*, 238.

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by thousands of hemophiliacs.¹³⁰ But it wouldn't be until April 1985 that the just-approved antibody test was used to screen all blood and plasma for HIV antibodies.

Eventually the blood-bank industry would pursue a three-pronged strategy for eliminating infected blood. Rather than focus on sexual orientation per se, a predonation questionnaire focused on more specific behaviors so donors, at least those who acknowledged their potential risk or actually knew they were HIV-positive, presumably would self-defer.

A second method was introduced in the form of a single box to check off whether one wanted his blood used only for research purposes rather than for actual transfusion. This "confidential unit exclusion" permitted those who felt pressured to donate to save face with coworkers-for example, while helping to minimize the risk to the blood supply by excluding their blood from actual transfusion.

Finally, of course, was actual antibody testing of the donated unit of blood itself after the test became available in early 1985.¹³¹

Since 1996, the American Red Cross has used even more sensitive tests that actually measure for the presence of the virus itself, rather than the ELISA's measurement of antibodies

¹³⁰. Donald P. Francis and James Chin, "The Prevention of Acquired Immunodeficiency Syndrome in the United States," *Journal of the American Medical Association* 257 (13 March 1987): 1357–66.

¹³¹. John C. Petricciani and Jay S. Epstein, "The Effects of the AIDS Epidemic on the Safety of the Nation's Blood Supply," *Public Health Reports* (May-June 1988): 236–41.

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to the virus. This has dramatically reduced the time, from an initial twenty-two days, in which it is possible to know whether an individual has been infected with HIV.

Although it boosted the cost of a pint of blood by as much as three dollars, the new test was expected to cut the risk of HIV infection from a blood transfusion to 1 in every 660,000 blood donations—a significant improvement over the 1 in 100,000 ratio in 1983, before HIV antibody testing was available.¹³² In fact, a 1996 study reported in the *New England Journal of Medicine* noted that the risk of HIV infection from a blood transfusion had now dropped to two in one million.¹³³

Today the Food and Drug Administration estimates that HIV risk in the United States from a unit of blood has been reduced to about one in two million. Now the risk is almost exclusively from so-called “window period” donations, the time very early after someone is infected when even current HIV testing methods can’t detect all infections.¹³⁴

The early foot-dragging of the blood industry and the manufacturers of Factor VIII would eventually cost not only thousands of lives but hundreds of millions of dollars in lawsuits as well. In late 1996, a federal judge approved a \$640 million settlement by four drug companies accused of knowingly selling

¹³². Sally Squires, “Blood Banks Adopt Stricter AIDS Test,” *Washington Post* (2 April 1996), Health section.

¹³³. Associated Press, “AIDS Risk in Transfusion Said to be 2 in 1 Million,” *Washington Post* (27 June 1996), A16.

¹³⁴. Food and Drug Administration (<http://www.fda.gov/BiologicsBloodVaccinesBloodBloodProducts/QuestionsaboutBlood/ucm108186.htm>), accessed 18 February 2010.

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HIV-tainted clotting products to about six thousand hemophiliacs in this country alone.¹³⁵

There were similar cases in other countries. In Canada, for example, health authorities in 1996 stripped the Red Cross of authority over that nation's blood supply because of the deterioration of public confidence after an estimated twelve hundred Canadian citizens were infected with HIV through transfusions in the 1980s.¹³⁶

Clearly, the blood and blood-products industries were responsible for circulating "bad blood" throughout the nation and the world. It cost them only money. It cost too many who trusted them their lives.

¹³⁵. Associated Press, "Settlement Is Approved in Hemophiliac Suit," *New York Times* (15 August 1996), D5.

¹³⁶. Howard Schneider, "Canada Reduces Red Cross's Authority," *Washington Post* (12 September 1996), A23.

SEVEN

Once the public became aware that whatever it was causing AIDS could be transmitted through the blood supply, fear, panic, and a pent-up hatred for homosexuals was unleashed in a sudden and virulent storm of media coverage. A June 1983 *New York* magazine cover story reported, “At the city Bureau of Preventable Disease, the telephone began ringing as many as fifty times a day with inquiries from fearful citizens. One caller was reassured that mosquitoes are not known to carry AIDS. Another was told that there is no reason to fire a maid simply because she is Haitian. Still another neighbor asked if she should worry about working with a homosexual.” In a telling description of the fear that had gripped the city, the article noted, “New York in 1983 has become a place where a woman telephones Montefiore Medical Center and asks if her children should wear gloves on the subway.”¹³⁷

Amidst this hysteria, Ginny Apuzzo’s fear that gay men would be stigmatized because of a belief that they were tainted by “bad blood” proved to be more than well-founded. Now those already inclined to hate gay people cloaked the daggers of their bigotry in the guise of concern for public health.

But gay men weren’t the first—and hardly the only—targets of this kind of scapegoating for a public health crisis. As Dennis Altman notes, “The idea that the nation’s blood supply was contaminated became a twentieth-century version of poisoning the

¹³⁷. Michael Daly, “AIDS Anxiety,” *New York* (20 June 1983), 25–29.

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wells (for which Jews were put to death during the Black Death).”¹³⁸

On May 25, 1983, Assistant Secretary for Health Edward Brandt announced that AIDS had become the government’s “number one health priority.” For the first time in the epidemic’s nearly two-year history at that point, the *New York Times* ran a front page article about it, reporting Brandt’s announcement. And as James Kinsella writes in *Covering the Plague*, “If it is in the *Times*, it is widely regarded as fact.”¹³⁹ Because the newspaper is considered to take a conservative approach to the news (despite its decidedly more progressive editorial page), and is required reading by executives in the news media, the placement of a story on the front page of the *Times* has a powerful influence on what other media consider newsworthy and important. It is not surprising, then, that in the spring of 1983 the American news media suddenly “discovered” that there was an epidemic underway. The result was what Dennis Altman called “the great media panic of 1983.”¹⁴⁰

Although *Newsweek* was the first major print outlet to report on AIDS among others besides gay men—hemophiliacs, injection drug users, and children—the *Times* and other media continued to focus exclusively on gay men. This was due at least in part to the fact that white middle-class gay men with AIDS were the most accessible to reporters—and because they “looked like” the mostly white middle-class reporters themselves.

¹³⁸. Altman, *AIDS in the Mind of America*, 74.

¹³⁹. James Kinsella, *Covering the Plague: AIDS and the American Media* (New Brunswick, NJ: Rutgers University Press, 1989), 71.

¹⁴⁰. Altman, *AIDS in the Mind of America*, 74.

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But the focus on gay men had the unintended effect of perpetuating the view that they were the only victims of the epidemic—and that AIDS was, by extension, a singularly white gay problem. Not only that, but the prevailing stereotype of an AIDS victim as a *white* gay man who lived in one or another of the nation's urban gay ghettos meant that gay men of color—as well as gay men who lived outside the major cities—would remain at great risk for years to come because of a lack of information about the disease. Neither the mainstream press nor the white gay community troubled themselves to understand that the gay community included more than just white gay men, and that only a small fraction of all gay people actually live in the urban gay ghettos. For their part, Black, Latino, and other nonwhite gay men could continue to deny their own risk—they were not, after all, white.

Gil Gerald, a longtime Black gay activist, first realized that AIDS was disproportionately affecting people of color after a staffer of the Gay Rights National Lobby in spring 1983 sent him copies of the *Morbidity and Mortality Weekly Report*. Gerald learned, for example, that while blacks comprised 12 percent of the population, they already were accounting for more than 20 percent of the nation's AIDS cases. When Gerald shared this information with a group of Black gay men who were board members of the National Coalition of Black Lesbians and Gays, they scoffed at it. At a reception at Gerald's home in Washington, D.C., he recalled the men saying, "No, Gil, this is all bullshit. They just want to change our sexuality—and [the only ones at risk are] guys like you who sleep with white guys." Ironically, Gerald notes, "Most of the people in that room went on to become prominent AIDS activists in D.C." On

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a more somber note, he added, "Most of the people in that room are gone."¹⁴¹

With the sudden interest in AIDS by the mainstream press, hysteria and sensationalism became the order of the day. They jumped all over an ill-informed and soon-debunked report in the *Journal of the American Medical Association* in May 1983 that whatever was causing AIDS could be transmitted through "routine household contact."

Arch-conservative columnist and inveterate presidential candidate Patrick Buchanan poured his own bit of poisonous rhetorical gas on the growing fire when he wrote that month in his syndicated newspaper column, "The poor homosexuals; they have declared war upon nature, and now nature is exacting an awful retribution."¹⁴² Somehow Buchanan's so-called "pro-life" views didn't extend to the lives of adults of whom he disapproved. And, of course, to acknowledge that AIDS was affecting others besides homosexuals would have further undercut his irrational and hateful diatribe.

Buchanan's compatriots in the Moral Majority found in AIDS an issue well suited to their efforts to wage cultural war against what they viewed as America's slide into godless immorality. In a 1983 fundraising letter, the Moral Majority argued: "Why should the taxpayers have to spend money to cure diseases that don't have to start in the first place? Let's help the drug users who want to be helped and the Haitian people. But let's

¹⁴¹. Gil Gerald, telephone interview with author, 25 August 1995.

¹⁴². Rodger Streitmatter, *Unspeakable: The Rise of the Gay and Lesbian Press in America* (Boston: Faber and Faber, 1995), 261.

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let the homosexual community do its own research. Why should American taxpayer have to bail out these perverted people?"¹⁴³

On July 17, 1983, gay San Francisco psychotherapist and AIDS activist Gary Walsh faced Moral Majority founder Reverend Jerry Falwell in a transcontinental television hookup for a show by San Francisco's ABC affiliate called "AIDS: The Anatomy of a Crisis."

Falwell opened his discussion with Dr. Mervyn Silverman, then director of San Francisco's Department of Public Health, *San Francisco Chronicle* AIDS reporter Randy Shilts, and Gary Walsh by quoting from St. Paul's Epistle to the Galatians: "When you violate moral, health, and hygiene laws, you reap the whirlwind," he said. "You cannot shake your fist in God's face and get away with it." Walsh told Falwell, "One of the most perverted uses of religion is to use religion to justify hatred for your fellow man." Falwell responded that he had "nothing but my compassion, love, and prayers" for Walsh.

Falwell craftily dodged Walsh's invitation to visit him in San Francisco to see firsthand the life Falwell had automatically condemned as "perverted." To prove his concern, however, Falwell noted that his church had seven psychiatrists and counselors standing by to help "cure" homosexuals. Walsh assured him it wasn't his homosexuality that needed to be cured.¹⁴⁴

¹⁴³. Cindy Patton, *Sex & Germs: The Politics of AIDS* (Boston: South End Press, 1985), 97.

¹⁴⁴. Shilts, *And the Band Played On*, 347–48.

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Others in the so-called Christian right exploited the public's fear of AIDS and hatred of gay people to raise money for organizations that purported to represent "family values." The American Family Association in winter 1983 sent a direct-mail fundraising letter that said, "Dear Family Member, Since AIDS is transmitted primarily by perverse [sic] homosexuals, your name on my national petition to quarantine all homosexual establishments is crucial to your family's health and security... These disease carrying deviants wander the street unconcerned, possibly making *you* their next victim. What else can you expect from sex-crazed degenerates but selfishness?"¹⁴⁵

Naturally these moralists refused to acknowledge the selflessness and self-sacrifice that many homosexuals were exhibiting at the time in caring for friends and lovers who were dying from AIDS. To do so would have meant being confronted by the fact that they were, as John Fortunato puts it in *AIDS, the Spiritual Dilemma*, promulgating "this grotesque perversion of Jesus' message of compassion that markets itself under the guise of born-again Christianity."¹⁴⁶

Gay leaders had good reason to fear a backlash that would irretrievably set back the community's efforts to achieve equal rights. The born-again right enjoyed both unprecedented access and influence in the Reagan White House. President Reagan's domestic policy adviser was none other than the outspokenly antigay Gary Bauer. A former director of the Family Research Council, Bauer today is president of something called American Values, which describes itself as a nonprofit organi-

¹⁴⁵. American Family Association letter (undated; circa winter 1983), quoted in Patton, *Sex & Germs*, 85.

¹⁴⁶. John Fortunato, *AIDS, the Spiritual Dilemma* (New York: Harper & Row, 1987), 86.

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zation “deeply committed to defending life, traditional marriage, and equipping our children with the values necessary to stand against liberal education and cultural forces.”¹⁴⁷

Jim Holm, a prominent gay activist in Seattle, told me, “Everything we had—a modicum of civil rights in certain well-educated larger cities, some freedom in some places such as the Castro to show such minor affectations as holding hands, the acceptance by the media of our spokespeople as legitimate news sources, the cooperation of friendly straight politicians such as mayors who restrained their homophobic police forces—was seen to be on the line.”¹⁴⁸

Writing in the *New Republic* in the summer of 1983, pundit Charles Krauthammer said, “How much of a national scientific effort we devote to fighting an illness is a reflection of the political value we attach to it and to its victims. But that is only the most superficial issue aroused by AIDS. The deeper issue is the moral value we attach to an illness, and on that may hinge the fate of the homosexual movement itself.” Krauthammer alluded to the former designation of homosexuality as a mental illness, noting, “Just as society was ready to grant that homosexuality is not illness, it is seized with the idea that homosexuality breeds illness.”¹⁴⁹

A week after Krauthammer’s article appeared, *Newsweek* ran a long article called “Gay America in Transition.” The maga-

¹⁴⁷. American Values, <www.ouramericanvalues.org>, accessed 21 March 2010.

¹⁴⁸. James Holm, letter to author, 15 September 1994.

¹⁴⁹. Charles Krauthammer, “The Politics of a Plague: Illness as Metaphor Revisited,” *The New Republic* (1 August 1983), 18.

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zine noted that, besides politicians using AIDS to justify anti-sodomy laws in Texas and Georgia, gay people had been told to leave restaurants, refused ambulance service, and evicted from their apartments simply because they were perceived as having AIDS.

In October 1983, New York physician Joseph Sonnabend was evicted from his office building on West Twelfth Street because of fear that his largely gay practice would bring down the building's market value. Boston's *Gay Community News* also reported that fall that corporate personnel managers were paying \$395 each to learn how legally to fire people with AIDS from their jobs.¹⁵⁰ They could have saved their money, because a 1986 decision by the Department of Justice, under Attorney General Edwin Meese, permitted the firing of anyone who was even perceived to have AIDS if coworkers were afraid of "catching" it.

The *Newsweek* article cited data from a Gallup poll indicating that 58 percent of Americans rejected homosexuality as an acceptable "alternative lifestyle." Taking a page from Jerry Falwell himself, the article went on to say "it is difficult for many straights to avoid the conclusion that nature or God is punishing homosexuals for defying sexual shibboleths that are as old as the Bible itself."¹⁵¹ Even Joan Collins, the bitchy star of "Dynasty," a television soap opera that was popular with many gay men in the early eighties, blamed AIDS on what she called the "moral laxity" of gay men.¹⁵²

¹⁵⁰. Streitmatter, *Unspeakable*, 18.

¹⁵¹. Tom Morganthau et al., "Gay America in Transition," *Newsweek* (8 August 1983), 30.

¹⁵². Altman, *AIDS in the Mind of America*, 69.

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Gay people who had only begun slightly more than a decade earlier to, as *Newsweek* put it, “enjoy, at best, a precarious tolerance in the public mind,” also wrestled with the taunts of internal demons that, even today, can nag at the mind and spirit of the most self-accepting homosexual. Richard Failla, described in the *Newsweek* article as “a professed homosexual who is a prominent New York City judge,” told the magazine, “The psychological impact of AIDS on the gay community is tremendous. It has done more to undermine the feelings of self-esteem than anything Anita Bryant could have ever done. Some people are saying, ‘Maybe we are wrong—maybe this is a punishment.’”

A mere decade after the American Psychiatric Association had removed homosexuality from its official list of mental illnesses, gay people feared that public hysteria over AIDS could lead to an attempt to “re-medicalize” homosexuality. Larry Mass told me he felt “the necessity to publicize the fact that we were dealing with this extreme health emergency that was quickly becoming unprecedented,” while at the same time “feeling a lot of pressure from a lot of people who wanted to jump on a bandwagon to say there was something deeply and seriously wrong with gay people.”¹⁵³ Mass had long feared that the anti-gay forces within psychiatry would cite the promiscuity and exorbitant rates of STDs among gay men as “evidence” of pathology, and try to reclassify homosexuality as a mental illness. What would they do now with a fatal STD that seemed to be targeting gay men so disproportionately?

In Provincetown, Massachusetts, the spit of land at the very tip of Cape Cod that for decades has enticed artists, bohemi-

¹⁵³. Lawrence D. Mass, M.D., interview with author, New York City, 28 April 1995.

VICTORY DEFERRED

ans, and homosexuals with its brilliant sunlight, stunning beaches, and acceptance of diversity, fear gripped heterosexuals and homosexuals alike. Alice Foley, a lesbian and longtime resident of the resort town, recalled in a 1995 interview how gay employees in her former restaurant, Alice's Café, reacted when a man with AIDS came in for dinner one night early in the epidemic.

"An entertainer here in town who was obviously sick came in the restaurant and ate," said Foley. "I remember the staff and myself in the kitchen talking. We didn't know what to do with his dishes, so we threw them out. That's when I said I've got to get more information on this shit—I can't keep throwing dishes away!"

Foley, who at the time was also Provincetown's director of public health (technically the town nurse) not only got more information but went on to become the local hero in P-town's efforts to address AIDS among its heavily gay population. She fought, sometimes against other gay people and often with the town's Rescue Squad, to procure or create services for people with AIDS—and, above all, to overcome fear with factual information. Foley told me that in the early eighties she used to have to park her car at least a block and a half away when visiting the home of someone known to have AIDS because the gay community was shunning those who were sick. "They were so frightened," she said. "Everyone was terrified."¹⁵⁴

¹⁵⁴. Alice Foley, interview with author, Provincetown, Mass., 30 July 1995.

EIGHT

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Obviously gay people were not immune to the panic that swept the nation, and the loyalty to the community by some gay men proved as fickle as that of all too many of their heterosexual supporters when they were confronted by AIDS. In a word, gay men were scared—and not merely of the much-feared political backlash. A bizarre and fatal disease of unknown origin and etiology had attacked them, the mysterious pathogen believed to cause it almost certainly transmitted through their most intimate acts of love and pleasure. They were scared for their very lives. Could any sexually active person at the time not have been frightened and at least a bit irrational?

EIGHT

Armed with a medical degree and a doctorate in retrovirology, experience working on feline leukemia virus—which causes an AIDS-like immunosuppression in cats—and in the CDC’s smallpox eradication program, Don Francis was in the right place at the right time when the AIDS epidemic began. His background working on epidemics and with gay men on the hepatitis B vaccine made him a valued member of CDC’s AIDS Task Force. But the globe-trotting, San Francisco-born scientist remained puzzled about one basic thing, and he knew he had to understand it if he, as a heterosexual doctor-researcher, was going to succeed in working with gay men being afflicted by AIDS: Why were gay men sexually attracted to other men?

“I was comfortable with gay men,” Francis said. When he realized he was going to be dealing with AIDS, he wanted to try to understand homosexual orientation. So he asked his friend Marcus Conant, a gay physician in San Francisco, “Why do you go around having sex with other men?” Francis recalled Conant saying, “Remember when you were a teenager and you started fucking around sexually, and you started being turned on with girls? Well, I had the same experience, but I was turned on with other boys.”

Francis was incredulous. As the two walked together on the streets of San Francisco, a couple came walking toward them. Conant asked, “Now see that, does that turn you on?” Francis answered, “Yes, when I see a good-looking woman coming down the street I get a little primitive urge.” Said Conant, “No, no, no—the guy walking with her!”

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The proverbial lightbulb came on for Francis. Still, he couldn't understand why gay men—at least the ones he had observed in his work, the men with many anonymous sexual partners and frequent STDs—were so promiscuous. Although he had begun to understand homosexuality and certainly knew firsthand the randiness of healthy men in general, Francis remained baffled at why so many gay men seemed to be drawn so easily into the world of sex clubs, bathhouses, and cruising in public parks—particularly when there was a deadly epidemic that seemed to be emanating from those very bastions of anonymous sex. For Francis, it was clear that, as he said to me, the “post-Stonewall commercialization of gay sex allowed an incredible amplification of an otherwise relatively difficult-to-transmit disease.”

Francis recognized the awkward position he was in, wedged between a gay community that was frightened and defensive, and a conservative Republican administration that would have preferred to see both gay men and “their” new disease quietly—and of course privately—eliminated from the nation's consciousness.

Speaking to a gay group in Los Angeles early in the epidemic, Francis recalled thinking, “I'm sitting here as a straight man who is employed by Ronald Reagan, my boss, and I'm telling gay men that I thought lots of sexual activity was a dangerous thing to do today.”¹⁵⁵ He realized he wasn't in the best position to be the bearer of such a message.

It certainly was a message many gay men did not want to hear. Some refused even to listen. For many homosexuals, gay liberation—and what it means to be gay—was inextricably linked to sexual freedom. The right to have sex anytime, any-

¹⁵⁵. Francis interview.

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where, and with anybody they chose was, for them, inalienable. So to suggest that they needed to limit their sexual behavior in *any* way represented for them an abridgment of their hard-won freedom and an untenable compromise of their very identity as gay men.

What's more, the fact that physicians—even if many of them were gay themselves—were urging gay men to restrain their sexual behavior brought back painful and angry memories from the recent past. After all it had been physicians, psychiatrists in particular, who considered gay people to be sick merely because they were not heterosexual.

Writing in GMHC's second newsletter in January 1983, Larry Mass reported that physicians were advising their gay patients, especially those in urban centers with large gay communities, to limit their sexual activity by having fewer partners, selecting partners known to be in good health, and limiting the number of different partners with whom they had sex. He added, "It is the increasing number of different sexual partners, not sex itself, that apparently increases the risk of developing AIDS."¹⁵⁶

Mass had been committed to being "sex-affirmative" since the seventies. But the advent of what was looking increasingly to be an epidemic caused by a fatal sexually transmitted infection challenged his commitment. He put out a twofold message, saying that while gay people shouldn't abandon their political struggle and commitment to fundamental civil liberties, they also had to recognize that in the midst of a public health emer-

¹⁵⁶. Noted in Mass, *Homosexuality and Sexuality: Dialogues of the Sexual Revolution*, vol. 1, 116.

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gency, precautions were necessary. “I would not allow myself to be put in a position of being sex-negative,” said Mass.¹⁵⁷

GMHC itself didn’t want to seem prudish. It certainly didn’t want to be perceived as telling gay men how to have sex. After all, another of the agency’s founders, novelist Edmund White, who co-wrote *The Joy of Gay Sex*, had been quoted in the seventies as saying that gay men should view their sexually transmitted diseases as “red badges of courage” in the sexual revolution.¹⁵⁸

Others in the community who were willing to speak out in support of more decisive changes in gay sexual behavior faced vicious criticism from gay men who were convinced they had “sold out” their gay birthright of free and easy sex—and that they likewise were selling the gay community down the river by not supporting the status quo of the ghetto.

Three New York men in particular faced condemnation, insult, and ostracism for daring to challenge GMHC’s unwillingness to speak frankly about the likely connection between sex and AIDS. Some vocal gay New Yorkers were enraged by a November 1982 article published by Michael Callen and Richard Berkowitz, both in their mid-twenties, diagnosed with AIDS, and patients of Joseph Sonnabend. Callen described the *Native* article, “We Know Who We Are: Two Gay Men Declare War on Promiscuity,” as “a blunt, provocative warning to gay men about the possible consequences of continuing to expose

¹⁵⁷. Mass interview.

¹⁵⁸. Quoted in Michael Callen, *Surviving AIDS* (New York: HarperCollins, 1990), 4.

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themselves to the diseases that were epidemic among promiscuous gay men.”¹⁵⁹

Callen and Berkowitz followed up their article in May 1983 with a forty-eight-page booklet, called *How to Have Sex in an Epidemic: One Approach*, paid for with Callen’s income tax refund. The booklet was the first publication ever to recommend that gay men use condoms in anal intercourse. The booklet, written by Callen and Berkowitz and informed by Sonnabend’s scientific and medical knowledge, *How to Have Sex in an Epidemic* recommended “avoiding the exchange of potentially infectious bodily fluids,” which eventually became the cornerstone of safe sex advice.

These men believed GMHC’s advice to limit the number, and assess the health, of one’s sexual partners was “dangerously inadequate.” In *Sex Positive*, a 2008 documentary about his early AIDS activism, Berkowitz said, “If they’re [GMHC] advising people to ‘cut down’ [on partners] when they believe one sexual contact can kill you, who the hell are they talking to? Who needs advice like that? Where are their minds? Where are their ethics?”¹⁶⁰

For their forward thinking, the men were roundly condemned—by GMHC and other gay men. Like others in the community, GMHC worried that publicizing the facts about gay promiscuity would hasten the impending backlash everyone

¹⁵⁹. Michael Callen and Richard Berkowitz, “We Know Who We Are: Two Gay Men Declare War on Promiscuity,” *New York New York Native* (8–21 November 1982). Quoted in Callen, *Surviving AIDS*, 6–7.

¹⁶⁰. Daryl Wein, *Sex Positive: The Richard Berkowitz Story* (2008).

VICTORY DEFERRED

feared. Callen noted, “GMHC and other critics retorted that by focusing attention on the incidence of the many sexually transmitted diseases common among promiscuous gay men, we were ‘shouting guilt from the rooftops,’” as Peter A. Seitzman, a gay physician, had put it in the *Native*.¹⁶¹

Callen believed passionately, some said fanatically, that promiscuity per se on top of a run-down immune system was the cause of AIDS. But others, who were receptive to whatever possibility science might eventually suggest was the cause, still felt it essential to keep the high level of promiscuity under wraps. Don’t air our dirty laundry in public, they reasoned, and the public will leave us alone.

Of course they would soon learn that the American public and the federal government were only too willing to let gay men suffer and struggle to address the AIDS epidemic on their own.

In his own front-page article in the *Native* in March of 1983, called “1,112 and Counting,” Larry Kramer echoed Callen and Berkowitz’s views—in the hyperbolic Kramer style that led soon thereafter to his ouster from GMHC’s board. “I am sick of guys who moan that giving up careless sex until this blows over is worse than death,” wrote Kramer. “How can they value life so little and cocks and asses so much? Come with me guys, while I visit a few of our friends in Intensive Care at [New York University]. Notice the looks in their eyes, guys. They’d give up sex forever if you could promise them life.”¹⁶²

¹⁶¹. Quotation is from Peter A. Seitzman, MD, “Guilt and AIDS,” *New York Native* (3–16 January 1983). In Callen, *Surviving AIDS*, 7.

¹⁶². Larry Kramer, “1,112 and Counting,” *New York Native* (14–27 March 1983).

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Besides galvanizing many gay people around the country to respond to AIDS on a political level, Kramer's article emboldened other gay men to speak out against a sexual lifestyle that now could end abruptly and hideously in an early grave.

In San Francisco, Bill Kraus and his fellow Harvey Milk Democratic Club members Cleve Jones and Ron Huberman—highly visible and well-liked men—published an article in the gay newspaper *Bay Area Reporter* that Randy Shilts said, “drew the battle lines on which [Kraus] would wage his fiercest political fight.” In the article, the men said, “We believe it is time to speak the simple truth—and to care enough about one another to act on it. Unsafe sex is—quite literally—killing us.” They went on, “Unsafe sex with a number of partners in San Francisco today carries a high risk of contracting AIDS and of death. So does having unsafe sex with others who have unsafe sex with a large number of partners. For this reason, unsafe sex at bathhouses and sex clubs is particularly dangerous.”

Given their political bent, the authors added, “If the gay movement means anything, it means learning self-respect and respect for one another. When a terrible disease means that we purchase our sexual freedom at the price of thousands of lives, self-respect dictates it is time to stop until it once again is safe.”¹⁶³

For their boldness, and despite years of service to the community, Kraus, Jones, and Huberman—exactly like Berkowitz, Callen, and Sonnabend in New York—were reviled in San Francisco as traitors to the “cause” by gay men who refused to distinguish sexual license from gay liberation. The community whose political interests they had championed

¹⁶³. Quoted in Shilts, *And the Band Played On*, 259–60.

VICTORY DEFERRED

alongside Harvey Milk himself treated them like pariahs. Jones recalled, “I had people spit on me on Castro Street, and call me a Nazi. And I thought I was a gay liberationist!”¹⁶⁴

Many gay men believed that people like Jones and Callen had been co-opted by the government or some other “enemy” of homosexuals into participating in a plot that would prevent them from having sex. Pat Norman told me, “People were not going to hear the doctors, or hear their friends or other people. They thought [safe sex] was some kind of homophobic strategy to keep people from having sex, to keep people from each other and paranoid about each other. People did not want to believe they were going to have to make such ‘severe’ changes in their lifestyle.”¹⁶⁵

San Francisco’s gay newspapers supported the denial of gay men who refused to believe that a major health crisis was underway. In large part this was because virtually all gay publications at the time depended upon the advertising revenue from bathhouses, bars, and sexually explicit services. The public health—and the very lives of gay men—mattered little to them in comparison to the money they stood to lose if they angered bathhouse owners by reporting honestly what was happening.

The *Sentinel* trivialized the medical research being done on AIDS. Offering its own theory of the cause of AIDS, the news-

¹⁶⁴. Cleve Jones, speaking on an “oral history” panel of long-time AIDS activists, at the National Skills Building Conference, sponsored by the National Minority AIDS Council, National Association of People with AIDS, and AIDS National Interfaith Network, in Atlanta, 31 October 1994.

¹⁶⁵. Norman interview.

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paper suggested that one thing unique about gay men was a stereotypical assumption that they all enjoy brunch—hence, a front-page April Fool’s joke: “Brunch Causes ‘Gay Cancer.’”

Another lead story a month later purported to be an investigation into the safety of bathhouses and sex clubs, but turned out to be about their lack of fire safety precautions rather than the sexual activity that went on in them. Rodger Streitmatter notes that the newspaper then “began waging a bare-knuckled attack not against the disease, but against an organization the community had created to *fight* the disease,” the K.S. Foundation (now known the San Francisco AIDS Foundation).

After the appearance of Kramer’s “1,112 and Counting” stirred up discussion among gay men about the epidemic, the *Bay Area Reporter* promised to “up the noise level on AIDS.” But, says Streitmatter, “rather than attacking the unrestrained promiscuity of the bathhouses, [*BAR* editor Paul] Lorch set his sights on AIDS patients and activists. Two weeks after upping the volume on the disease, Lorch denounced patients as free-loaders and activists as fanatics.”

When a group of twenty-two AIDS patients wrote *BAR* publisher Bob Ross to criticize Lorch’s coverage—the *Sentinel* actually got hold of their letter and published it on its own front page—Lorch kept their letter and, in one of the more reprehensible acts of the epidemic, checked off the signers’ names as they one-by-one succumbed to AIDS.¹⁶⁶

Kramer had singled out the nationally circulated *Advocate* in “1,112 and Counting.” He wrote, “I am sick of the *Advocate*, one of the country’s largest gay publications, which has yet to quite acknowledge that there’s anything going on. That newspaper’s

¹⁶⁶. Streitmatter, *Unspeakable*, 252–59.

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recent AIDS issue was so innocuous you'd have thought all we were going through was little worse than a rage of the latest designer flu. And their own associate editor, Brent Harris, died from AIDS. Figure that one out."

In 1982, the *Advocate* had declined to publish Larry Mass's "Basic Questions and Answers About AID"—despite the fact that it was one of the only information sources available about the epidemic "during a period when no other such information was being featured," as the magazine's own history reported it. In fact, it wasn't until April 1983 that the *Advocate* tepidly suggested that the "use of condoms may be helpful" for gay men engaging in anal intercourse.

At the *San Francisco Chronicle*, Randy Shilts began in May 1983 to focus attention on the bathhouses—and to become himself a lightning rod for the wrath of those in the community who considered them sacrosanct. Shilts was demonized for daring to question the judgment of some gay people in the pages of a so-called "straight" newspaper, rather than simply bowing to the pressures of gay activists to keep it as it were "in the family." As the city's annual Gay Freedom Day Parade approached, Shilts's May 27, 1983, article, "Gay Freedom Day Raises AIDS Worries" quoted public health director Mervyn Silverman as saying, "There has been some pressure on me to close the bathhouses."

But Silverman left it to gay men to monitor their own behavior, and trusted that out-of-town visitors coming for Gay Freedom Day "will realize they can't do the kinds of things they might do at home."¹⁶⁷ Silverman did, however, require that bathhouses post warning notices about AIDS.

¹⁶⁷. Randy Shilts, "Gay Freedom Day Raises AIDS Worries," *San Francisco Chronicle* (27 May 1983).

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In his own effort to alert gay men to the risks of unsafe sex in the baths, Shilts attempted throughout 1983 and 1984 to get his articles about the risks of promiscuity and the bathhouses published on Fridays, before gay men headed out for a weekend of fun. As he put it, “I wanted everyone to have the fear of God in them.”¹⁶⁸

As gay activists battled one another over the bathhouses, they demonstrated—as they are wont to do—how little their ideologically driven arguments had to do with the real lives of most gay men. According to the estimate of Sal Accardi, the owner of a large bathhouse in San Jose, attendance at the baths in San Francisco dropped by 65 percent in 1983.¹⁶⁹

Half a dozen of the city’s twenty bathhouses closed, including the Caldron, Cornholes, Liberty Baths, Sutro Baths, and Bulldog Baths. The owner of the Hothouse said he closed the bathhouses because his business had been cut in half by the fear of AIDS.¹⁷⁰ It seemed the gay rank and file were catching on to the idea of safe sex—or were at least having their sex outside the bathhouses.

In February 1984, the CDC’s Jim Curran said, “I wish the gay community would officially express concern over the bathhouses. I’d like to see all bathhouses go out of business. I’ve told bathhouse owners they should diversify and go into something healthy—like become gymnasiums. Gay men need to

¹⁶⁸. Quoted in Kinsella, *Covering the Plague*, 173.

¹⁶⁹. Altman, *AIDS*, 149.

¹⁷⁰. “Garage Sale Marks Closing at Baths,” *Gay Community News* (10 September 1983), 2.

VICTORY DEFERRED

know that if they're going to have promiscuous sex, they'll have the life expectancy of people in the developing world."

Openly gay city supervisor Harry Britt announced plans to meet with doctors and AIDS researchers to organize a campaign to inform gay men that "sexual activity in places like baths or sex clubs should no longer be associated with pleasure—it should be associated with death."¹⁷¹

The following month, longtime gay activist Larry Littlejohn—who in 1964 founded San Francisco's pioneering gay group, the Society for Individual Rights—announced that he would move to place a measure on a citywide ballot to prohibit sexual activity in the baths. Many believed the ballot measure would pass.

Pressured to move against the baths, but still hoping the gay community itself would act against them, Silverman on April 9, 1984, proposed a ban on sexual activity in the baths, rather than an outright closure as some were hoping.

Coincidentally, the same day, *Time* magazine published a cover story announcing the end of the so-called sexual revolution. In view of the fear of AIDS gripping the nation at that point, and the increasing deaths of gay men, it is nothing short of astounding to note that the 4600-word article never once mentioned the epidemic. And homosexuality—not homosexuals themselves—is mentioned only in one sentence in the final paragraph, together with porn on television and teenage sex, as part of what the magazine called "the gray area."¹⁷² If we

¹⁷¹. Shilts, *And the Band Played On*, 416.

¹⁷². John Leo, "The Revolution Is Over: In the '80s, Caution and Commitment are the Watchwords," *Time* (April 1984).

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were to gauge the nation's awareness of AIDS and gay people from one of its leading news magazines at that point, we would conclude that America simply didn't want to know.

More than a decade later, Silverman recalled that he continued to hope the gay community itself would take responsibility for dealing with the issue of sex in the bathhouses. "I felt that since it was a situation having to do with sex," he said, "the government never dealt well with those issues."

The gay community had dealt effectively with other gay-owned businesses that were in violation of city health or safety codes, and Silverman felt they would do so again. When some gay bars had only one exit, making them a fire hazard, gay people set up pickets and information tables outside. Said Silverman, "It didn't take long for the facilities to change." Silverman pursued people within the gay community, saying, "Why don't you all do what you did with fire hazards? Get out there and really do something to get them to clean up their act."¹⁷³

As controversy swirled around the issue of the bathhouses, Health and Human Services Secretary Margaret Heckler announced on April 23, 1984, that government scientists had discovered the cause of AIDS: a retrovirus dubbed HTLV-III (Human T-cell lymphadenopathy virus type III). A late 1986 compromise between the American (who called it HTLV-III) and the French (LAV, or lymphadenopathy-associated virus) "co-discoverers" of the virus, led to a renaming of the virus as human immunodeficiency virus, or HIV.

Besides lauding the efforts of National Cancer Institute researcher Robert Gallo—and giving a passing nod to the Pas-

¹⁷³. Mervyn Silverman, MD, telephone interview with author, 15 February 1995.

VICTORY DEFERRED

teur Institute researchers in Paris who technically had discovered the virus that Gallo was then able to reproduce in large quantities—Heckler promised there would be a blood test within six months and a vaccine inside of two years. Her groundless promise stunned the scientists listening to her. But her words gave hope to a gay community that was reeling from fear, grief, confusion, and its own internecine battles over sex.

The day of Heckler's announcement there were 4,177 reported AIDS cases in forty-five states—including more than sixteen hundred in New York City alone, and more than five hundred in San Francisco.

San Francisco mayor Dianne Feinstein resisted closing down the bathhouses lest such a move be seen as a political, rather than public health, decision. Instead she pressured Silverman to do it. Part of Silverman's reluctance to take action—besides his characteristic style of consensus-seeking—was a fear that closing the baths in San Francisco would be viewed nationally as a move against gay people in the country's most liberal city. As he put it, "If San Francisco, as a bastion of liberalism, closed down the baths, what impact would that have on other communities?" Would it mean gay bars would be closed next? That sodomy laws would be either instituted or acted upon?

As Silverman and others grappled with these volatile issues, a group of gay men, clad only in towels, demonstrated at one of the health director's press conferences, carrying placards saying, "Today the tubs, tomorrow your bedrooms" and "Out of the Baths, Into the Ovens."

A proposal by Jim Ferels, head of the K.S./AIDS foundation, to impose a "safe sex code" on all gay sex venues seemed to be headed in the right direction. Ferels' plan, which he had

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worked out with the gay political clubs, would mandate that the baths and sex clubs give space to posters, literature, condoms, lubricants, public service announcements, minimum lighting standards, and educators from AIDS information groups.¹⁷⁴

But just before the foundation was to announce its plan publicly, Silverman finally took action and closed down the city's remaining bathhouses and sex clubs. Speaking more forcefully than he had up until then, Silverman announced at an October 9 press conference that he had ordered the closure of the city's fourteen remaining bathhouses that "promote and profit from the spread of AIDS." The health chief was blunt. "Make no mistake about it," he said. "These fourteen establishments are not fostering gay liberation. They are fostering disease and death."¹⁷⁵

The baths reopened within hours, and forced the city to take the matter to court. Seven weeks later, the state superior court ruled that the baths could remain open—but only under the conditions that they no longer provide private rooms and have monitors available to prevent high-risk sex.

In other cities, there were debates over bathhouses, often with the same kind of rancor and resistance—also with more outright political, as opposed to public health, justifications—as in San Francisco. New York City and Los Angeles closed down their bathhouses within a year after San Francisco. New York health authorities in November 1985 closed down the Mine Shaft, the bar famous for the raunchy, no-holds-barred sex it allowed.

¹⁷⁴. Brian Jones, "Community Plan to Regulate Baths," *Bay Area Reporter* (27 September 1984).

¹⁷⁵. Shilts, *And the Band Played On*, 489.

VICTORY DEFERRED

In Miami, Shilts reported that Club Baths owner Jack Campbell “brushed off questions about the baths’ role in the epidemic by insisting that most of Florida’s AIDS cases were Haitians, and it wasn’t a problem for gays.”¹⁷⁶ Of course this was specious, as most of the early AIDS cases in Miami—as in the rest of the country—were among sexually active gay men of all races. But Campbell’s financial and political clout provided him with an effective shield against criticism by gay leaders.

In Chicago, David Ostrow left Howard Brown, which he had helped to found, in part because the agency’s leadership—as associates of Chuck Renslow, owner of the city’s largest bathhouses and several bars—handled the bathhouse issue with kid gloves lest they incur the wrath of their patron. Said Ostrow, “I thought it was inappropriate for the head of the baths to have so much control over the clinic. But of course he had a lot of political clout.”

Although Ostrow firmly believed the baths should be allowed to stay open, and could be effective venues in which to provide prevention education, he brooked no disagreement on the pivotal role the bathhouses played in widely disseminating HIV among gay men. “Normally,” he explained, “people have sex within a social network of a certain race, age, and economic status. In the bathhouses, you had sex with anybody you wanted to have sex with, and they went on to have sex with others. So not only do you spread it rapidly in the bathhouses, but you spread it into all sectors of the community that are in that bathhouses and they go out and spread it.”¹⁷⁷ Even lots of

¹⁷⁶. Ibid., 306.

¹⁷⁷. David G. Ostrow, MD, interview with author, Chicago, 3 June 1995.

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sex within a closed network would keep the virus in check, Ostrow said. But the mingling at the baths literally “amplified” HIV far and wide among American and Western European gay men.

Would the community have resisted less if gay men had been more confident that their basic human rights were not at stake in the debate over sex and bathhouses? Of course it’s impossible to know with certainty. The more important, because more fundamental—and still unanswered—question is whether gay men would have attached so much value to sex itself if they had been treated as full human beings, and offered the same rights as heterosexual Americans, including the social and legal approbation of their relationships. Larry Mass’s suggestion that promiscuity would diminish if gay relationships were accorded the same recognition, support—and expectations of mutual commitment—as those of heterosexuals continues to make good sense three decades on. It also continues to be mostly ignored.

To stem the further spread of HIV among gay men, the community struggled to figure out, as Callen and Berkowitz’s ground-breaking booklet put it, “how to have sex in an epidemic.” Too often the struggle was with one another, as anyone who questioned the promiscuous status quo of the ghetto was derided as a traitor to the “cause” of gay liberation.

At the same time gay men managed to accomplish the most remarkable degrees of behavior change ever seen in the history of medicine, they chafed against the second-rate role they were cast in as the whipping boys and worst nightmares of mainstream America. The old demons of guilt and shame still haunted them, reinforced by the condemnation of the religionists who now slandered all gay men as “disease-carrying deviants.”

VICTORY DEFERRED

Before disparaging the way gay men dealt with AIDS in the early years, a bit of perspective is highly recommended. As even Randy Shilts conceded—despite his own antipromiscuity agenda—“The gay response to the bathhouse problem was not a homosexual reaction; it was a human reaction.”¹⁷⁸ In the years ahead, gay men would demonstrate a profound humanity as they transcended their own fears, doubts, and outlaw status to care for one another. The darkness of hatred, internal and external, would yield to the brilliant light of love as gay people rallied a true “army of lovers”—a national and global movement of caring, involved people—to fight the viral scourge, bind the wounds of the stricken, and prevent the further destruction to their lives and community.

¹⁷⁸. Shilts, *And the Band Played On*, 415.

PART 3

RALLYING THE TROOPS

Thou shalt love thy neighbor as thyself.

LEVITICUS 19:18

The personal was never so political as when the personalities of local elected officials, their public health chiefs, and gay activists defined the ways that people with AIDS would be cared for. The degree of visibility, acceptance, and influence of gay people in the nation's hardest-hit cities determined the parameters of caring, funding, and support. Gay people themselves argued over whether to stick to providing palliative care for the stricken or to channel the extraordinary outpouring of community support into the gay civil rights movement. Gay doctors and lawyers used their professional skills to help people with AIDS maneuver through the medical and legal minefields they were forced into by a disease that seemed to underscore their social status as "outsiders." Black gay men who felt like outsiders wherever they were, found that the only thing to do—as it was for their white brothers—was to say "Enough of the charade!" For everyone who cared enough to get involved, the practical love they gave and received among the ruins of lives shattered by illness and death helped to heal their own emotional and spiritual wounds.

NINE

In the grand foyer of San Francisco's City Hall is a bronze bust of George R. Moscone, the city's mayor from January 1976 until his assassination, with gay supervisor Harvey Milk, in November 1978. Beneath it is engraved a Moscone quotation about what makes San Francisco unique. As I paused to read it, I understood more clearly why San Francisco was able quickly to mount what became a model of compassionate, coordinated AIDS services. The fallen mayor said, "San Francisco is an extraordinary city, because its people have learned to live together with one another, to respect each other, and to work with each other for the future of their community. That's the strength and the beauty of this city—and it's the reason why the citizens who live here are the luckiest people in the world."

I was at City Hall to interview Margaret Kisliuk, the city's lobbyist in Sacramento. When Dianne Feinstein became mayor, after Moscone's assassination, Kisliuk was her liaison to the public health department. Her role in Feinstein's office became increasingly important as AIDS began to strike gay men in the city, and as the mayor sought to balance the demands of public health and the realities of politics.

Fortunately for those afflicted by AIDS, Kisliuk explained, the city in the early eighties was enjoying a budget surplus; the mayor was the daughter, wife, and mother of doctors, and so was receptive to the counsel of public health and medical leaders; and the gay community already had enjoyed years of political clout unknown anywhere else in the country. In addition, the city's legislator in Sacramento—Willie Brown, later San Francisco's mayor from January 1996 to January 2004—was

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Speaker of the State Assembly, and could use his considerable power to steer state funding to his hometown.¹⁷⁹

Peter Nardoza, Kisliuk's colleague in the mayor's office, was Feinstein's unofficial liaison to the gay community. Nardoza concurred in an interview with the reasons that Kisliuk suggested were behind the city's early and effective AIDS response. But he added that perhaps the most important reason Mayor Feinstein was able and willing to view AIDS as a health concern—rather than as the political hot-button issue it became for, say, the federal government—was that she had gay friends.

Echoing Armistead Maupin's description of the city in the seventies, Nardoza said, "No matter where you went, gay and straight people meshed in a very comfortable blend." When AIDS appeared, then, the mayor, the public health director, and the board of supervisors were supportive because they all personally knew gay people. As Nardoza said of the mayor, "In her mind, it wasn't a matter of '*they* are dying.' It was '*we* have a problem.'" ¹⁸⁰

San Francisco's ability to deal with AIDS had everything to do with its willingness to muster financial resources and political support, even as other cities and the federal government equivocated as to whether and to what extent they ought to be involved in addressing what they saw as a "gay plague." In New York, the epidemic's East Coast epicenter, gay people certainly were visible. But the gay vote was fractured and not viewed as a serious political force among the city's many competing sub-

¹⁷⁹. Margaret Kisliuk, interview with author, San Francisco, 3 February 1995.

¹⁸⁰. Peter Nardoza, interview with author, San Francisco, 29 January 1995.

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communities. An outspoken and highly conservative Roman Catholic archbishop watched like a hawk for anything that might threaten his moral authority. And a bachelor mayor who for years had dodged rumors that he was gay couldn't afford to be seen as too supportive of homosexuals.

A city far bigger than San Francisco, New York staggered under the weight of social and infrastructure burdens largely unfamiliar to the city by the bay. According to Stephen C. Joseph, New York City's director of public health from 1986 to 1990, the problems plaguing the city and contributing to its slow response to AIDS included a huge homeless population, an estimated two hundred thousand heroin addicts, a shortage of low- and middle-income housing, a growing prison population, and a federal policy in the Reagan years that abandoned the nation's cities. As Joseph put it in *Dragon Within the Gates*, "In the sea of New York's troubles, AIDS was just one more rock dropped into the waves."¹⁸¹

As it is in so many other ways, New York in the AIDS epidemic would prove to be in a class by itself. The city's large numbers of injection drug users meant that from the early years of the epidemic, the sharing of needles was as much a source of infection among its many poor heterosexual Blacks and Hispanics as unprotected anal intercourse was among white middle-class gay men. With a relatively small population of users in San Francisco, that city's AIDS epidemic would continue to the present day overwhelmingly to affect gay men. These were the two poles of virtually the entire AIDS pandemic in America: an affliction mainly of injection drug users and their sexual partners

¹⁸¹. Stephen C. Joseph, M.D., *Dragon Within the Gates: The Once and Future AIDS Epidemic* (New York: Carroll and Graf, 1992), 69.

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in areas where there are many of them, and of gay and bisexual men virtually everywhere else in the country.

Besides the differences between their respective cities and the epidemics in them, the personal nature of the two cities' public health directors at the start of the epidemic also shaped their responses in important ways. From his 1977 appointment by Mayor Moscone, Mervyn Silverman had directed the health department in San Francisco with the kind of consensus-seeking style he'd developed in the Peace Corps and the sensitivity to citizen "consumers" he had cultivated as director of community affairs for the Food and Drug Administration. In 1982, New York hired David Sencer, the former director of the Centers for Disease Control, to be its public health director.

During his tenure at CDC, Sencer had presided over two major public health events in which ineptitude in one case, and intentional neglect in the other, would echo into the 1980s and beyond in the AIDS epidemic. Under Sencer's direction, the CDC in 1976 projected an epidemic of swine flu and called for the inoculation of every American man, woman, and child. This was based on the death from swine flu of one soldier. After the government spent millions of dollars on vaccine, fifty-eight people died from a wasting neurological disease caused by the vaccine itself. The dead soldier remained the nation's only case of swine flu. Also in the bicentennial year, the outbreak of a strange bacterial disease among a convention of American Legion members prompted panic and the rapid deployment of public health forces. This was a sharp contrast to the decades-long Tuskegee experiments in which federal government scientists observed poor Black men afflicted by syphilis, without offering readily available and simple treatment, merely to learn the natural history of the disease. On Sencer's watch, the CDC finally investigated the matter.

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Perhaps Sencer was merely continuing the government's tradition, established in Tuskegee, of downplaying the medical catastrophes afflicting unpopular groups of people when he repeatedly denied the impact and importance of AIDS. Randy Shilts reported that Sencer stated in 1983 that AIDS was not a major problem in New York. In 1985 he again dismissed the suggestion that AIDS was a "crisis" in the city—despite the fact that by then there already were three thousand cases in New York alone.¹⁸²

In an empty gesture to the gay community, Sencer in March 1983 created the Office of Gay and Lesbian Health Concerns, directed by gay physician Roger Enlow, within the department of public health, to serve as a focal point for its meager efforts against AIDS. He did so only after gay community leaders, in a letter to Mayor Ed Koch from the AIDS Network, penned by Larry Kramer, warned, "the gay community is growing increasingly aroused and concerned and angry."¹⁸³ As Dennis Altman has pointed out, the establishment of the office was "an odd response to the epidemic in a city where almost a third of the cases are not gay."¹⁸⁴

For the next couple of years, New York continued to make gestures to show "concern"—a few small grants here and there—but had no systematic response. San Francisco, on the other

¹⁸². Randy Shilts, *And the Band Played On* (New York: St. Martin's Press, 1987), 310, 533.

¹⁸³. Larry Kramer, "The AIDS Network Letter to Mayor Koch," in *Reports from the holocaust: The Making of an AIDS Activist* (New York: St. Martin's Press, 1989), 53.

¹⁸⁴. Dennis Altman, *AIDS in the Mind of America* (Garden City, NY: Anchor Press/Doubleday, 1986), 129.

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hand, gave millions of dollars for AIDS services. By mid-1983, the city already had spent more than \$3 million for AIDS—at that point more than the entire AIDS extramural research budget of the National Institutes of Health.¹⁸⁵ New York, with the nation's highest number of AIDS cases, left it to the gay community to fend for itself. San Francisco recognized that each of its diverse subcommunities was an essential part of the whole. The responses of cities and towns across the US varied between these two approaches.

Not long after the first cases of AIDS were reported, Larry Kramer wrote in the *New York Native*, "This is our disease and we must take care of each other and ourselves."¹⁸⁶ In August 1981, Kramer hosted a meeting at his home of gay men interested in learning what little was then known about the strange diseases that already had killed some of their friends.

The following January, Kramer and five other well-known gay men—Nathan Fain, Larry Mass, Paul Popham, Paul Rapoport, and Edmund White—gathered again at Kramer's apartment near Washington Square. From their meeting came a new organization they called, straightforwardly, Gay Men's Health Crisis, which they created as a means to share information with gay men and raise money for medical research. As with many AIDS organizations that would form in later years, GMHC's first service was a hotline—originally nothing more than the answering service of Rodger McFarlane, Kramer's boyfriend at the time.

GMHC initially was a kind of ad hoc committee of volunteers who contributed time and created services according to their

¹⁸⁵. Shilts, *And the Band Played On*, 311.

¹⁸⁶. Kramer, *Reports from the holocaust*, 9.

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interests and abilities. Larry Kramer recalled, “We almost allowed anybody to do anything if they seemed responsible and passionate about it—whether it was doing an epidemiological study, or wanting to start a buddy system, or translating some stuff into Spanish that we would give out at the bars, or designing a brochure, or putting out a newsletter. We didn’t have an office; we met in different people’s apartments every week.”¹⁸⁷

By the time of its first anniversary, GMHC had grown from its original six founders to more than three hundred volunteers. GMHC’s board noted in its second newsletter that the group had raised more than \$150,000; distributed twenty-five thousand copies of its first, and one hundred thousand copies of its second, newsletter; produced three hundred thousand brochures (in English, Spanish, Creole, and French); fielded almost five thousand hotline calls; formed a network of “buddies” to provide practical support for people with AIDS; provided legal and financial advisers; organized community forums; trained medical professionals; and served as a source of information about AIDS for the news media. All of its services were provided by volunteers and were offered free.

Written by Kramer, the board’s statement in the newsletter continued, “We have never encountered so much love between men as we have felt at GMHC, and watching this organization grow in response to our community’s terrible new needs has been one of the most moving experiences we have ever been privileged to share.”¹⁸⁸

¹⁸⁷. Larry Kramer, interview with author, New York City, 4 March 1995.

¹⁸⁸. Kramer, *Reports from the holocaust*, 30.

VICTORY DEFERRED

From its inception, Kramer and cofounder Paul Popham, GMHC's first president, disagreed about the organization's mission. Their competing visions would lead within a year of the organization's founding to Kramer's ouster from the board, and years of antipathy that would be resolved only when Popham himself was nearing death from AIDS in 1987. Beyond the personal nature of the disagreement, the two sides represented a split that would remain at the core of GMHC's identity for many years.

As Kramer tells it, his own vision "was to spread information, fight and confront the system." On the other hand, he said that Popham, "who was in the closet and who was supported pretty much by the board, felt that we should very quietly take care of ourselves."

Another GMHC cofounder, Larry Mass, recalled it somewhat differently. "Paul Popham's thing was to get this organization to work," said Mass. "Larry's thing was not compromising." He added, "We wanted to get a legitimate organization going—something like the American Heart Association, or American Cancer Society. A level of radical protesting was necessary, but not for this organization. It was primarily to be an information and service organization."¹⁸⁹

Lost in the gulf of anger and hurt feelings that divided GMHC's founders was Kramer's important critique of how the gay community's lack of political clout in New York had forced it to create a parallel health care and social welfare system to educate the gay community and serve those with AIDS. In San Francisco, as Kramer constantly pointed out, the city simply funded existing organizations in the community to provide AIDS

¹⁸⁹. Lawrence D. Mass, MD, interview with author, New York City, 28 April 1995.

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services. Said Kramer, “If we quietly take care of ourselves, we are saying not only that the system isn’t *going* to help us, but we’re not *making* the system help us. We’re paying twice for the services—what we’re paying for the city and state to provide from our taxes, and what we’re also giving GMHC contributions to do.”¹⁹⁰

Kramer dramatized the situation in his 1985 play *The Normal Heart*. In it, the playwright’s alter ego, Ned Weeks—portrayed by Brad Davis, who died from AIDS in 1991—complains about GMHC (unnamed in the play, but clearly the subject). “Now they’ve decided they only want to take care of patients—crisis counseling, support groups, home attendants. ...I know that’s important, too. But I thought I was starting with a bunch of Ralph Naders and Green Berets, and the first instant they have to take a stand on a political issue and fight, almost in front of my eyes they turn into a bunch of nurses’ aides.” When the play opened at New York’s Public Theater, on April 21, 1985, the whitewashed plywood walls of the set were painted with facts, figures, and names relevant to the burgeoning AIDS crisis. Among them were these: “MAYOR KOCH: \$75,000—MAYOR FEINSTEIN: \$16,000,000,” a reference to the wide disparity between the commitments of New York and San Francisco for public education and community services.¹⁹¹

When Marcus Conant arrived in San Francisco in 1965, the young dermatologist volunteered to work one night a week at the Haight Ashbury Free Clinic. While he was there, he observed some of the country’s earliest cases of genital herpes, then beginning to run rampant among the free love crowd.

¹⁹⁰. Kramer interview.

¹⁹¹. Larry Kramer, *The Normal Heart* (New York: Penguin Books, 1985).

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“Those kids in the late sixties were sleeping with whoever was available,” said Conant. He formed a clinic at the University of California–San Francisco to study the disease.

In early July 1981, Conant organized another multidisciplinary clinic at the university; this time, the patients were gay men, like Conant himself. His phone conversations earlier in the year with his friend and fellow herpes expert Alfred Friedman-Kien, convinced Conant that San Francisco needed to brace itself for what he expected would be an onslaught of Kaposi’s sarcoma cases. The KS Clinic solicited patients from the city’s physicians, who were only too glad to refer them because, as Conant explained, “They knew it was a fatal disease; they were scared of it; they didn’t know anything about it; and they couldn’t offer the patient anything.”

The following May, Conant realized that his clinic would have no end of patients if something wasn’t done to try to prevent them from becoming sick in the first place. He said to himself, “Wait a minute. It’s not enough to sit up here in your ivory tower and diagnose them, you’ve got to get out there and stop it.”¹⁹² Recognizing that he needed political support in the community to form an organization to provide information about the new disease, Conant contacted Harvey Milk’s protégé Cleve Jones, then an aide to city supervisor (and future mayor) Art Agnos.

Jones recalled, “Marcus said he wanted to start a foundation, and I said I would help him. I had the political knowledge and connections. He brought Frank Jacobson, who has since died, and Paul Volberding, from the General [hospital]. We also got Bob Ross, who [was] the publisher of the *BAR* [*Bay Area*

¹⁹². Marcus Conant, MD, interview with author, Washington, DC, 13 July 1995.

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Reporter], the gay paper. And we set up the Kaposi's Sarcoma Research and Education Foundation."

The group had little information to give out, so little was known about AIDS then. "We rented this one room on Castro Street, and had one phone line," Jones told me. "That phone line started ringing—and it never stopped." Young men began showing up with purple spots on their feet. There were no services available at the time, nowhere for these men to go except the K.S. Foundation. Said Jones, "People would call and all we could really say was 'we care,' and 'give us your name and number.'"

Like Kramer, Jones recognized that the community's response to AIDS had enormous political implications. "It was the beginning of this incredible grassroots movement," he said. In the foundation's first year, Jones would go down onto Castro Street and wait for someone he knew to walk by. He recalled, "I'd say 'You! How would you like to serve your people? Come up here and answer my phone would you?'" Those young gay men were the first class of recruits in the fight against AIDS. Said Jones, "Many of them now hold high administrative positions. Many are dead."¹⁹³

In addition to the K.S. Foundation, a second organization in San Francisco found new life in providing support services to men facing certain death from AIDS. Psychologist Charles Garfield in 1975 founded the Shanti Project in Berkeley, across the bay from San Francisco, after he was asked to monitor the psychosocial needs of patients in the cancer institute where he was working at the time. Shanti put out word that the project needed volunteers, who would be trained to provide emotional

¹⁹³. Cleve Jones, interview with author, San Francisco, 2 February 1995.

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and practical support services to terminally ill cancer patients and their survivors.

As far back as five years before the first reported cases of AIDS, Garfield told me, something odd seemed to be happening at Shanti. “As early as 1976,” he said, “we started getting calls from the gay community that seemed out of proportion to the population. I had a feeling that it doesn’t make sense for there to be a ‘gay cancer.’ How does that cancer differentiate between gay and non-gay?”¹⁹⁴

Efficient management was never Shanti’s strong suit, and by the time KS—which gay men themselves dubbed “gay cancer”—was first reported officially in 1981, the organization was languishing. But after relocating to San Francisco, and an infusion of cash from the city government, Shanti (whose name in Sanskrit means “the peace that surpasses all understanding”) volunteers began to serve gay men with AIDS. Within a few years, the Shanti model of AIDS services became famous and widely emulated throughout the country.

Helen Schietinger became the nurse coordinator of Marc Conant’s KS Clinic shortly after its formation in 1981. “I thought, ‘Good Lord, why are gay men getting cancer?’” Schietinger recalled. “It doesn’t make sense. But it sure sounds like a place where I, as a lesbian, could be useful.” The counseling degree Schietinger had earned to augment her nursing skills soon led her to take more than a research interest in the gay men coming into the clinic. “I was providing emotional support to them as they were getting worked up by these doctors,” she said, “and then trying to find ways for them to get support in the community.”

¹⁹⁴. Charles Garfield, telephone conversation with author, Washington, DC, 17 November 1995.

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After eighteen months at the clinic, Schietinger realized that she was mainly interested in trying to ensure that “people who were being told that they had this scary cancer” found support. The only place in the city for them was Shanti, which had begun to offer support groups. Schietinger realized that Shanti would be the best place for her to work with men affected by the new disease, so she went over to Shanti to put together a new AIDS housing program. “It was wonderful to become part of a community-based organization and make something happen that needed to happen,” she said.¹⁹⁵

Like Shanti, gay health clinics across the country—created in the 1970s to treat gay men for the sexually transmitted infections raging among them like wildfire—expanded into providing AIDS services as a natural extension of the work they already were doing in the community. They had certain advantages over the newly formed AIDS service organizations, such as GMHC and the K.S. Foundation, in that they already had visibility in the community, organizational infrastructures, and valuable connections with the medical and research communities going back to the hepatitis B studies of the late seventies.

Even in the seventies, the clinics had dispensed both penicillin and politics as they became important institutions in the gay community. In the AIDS epidemic, their roots in the feminist and lesbian health movements showed as they readily grasped the inherently political nature of the epidemic and government’s faltering response to it. Experienced in treating STDs, though, even these seasoned organizations learned quickly that a fatal STD, which gradually undermined an individual’s health, required a whole new way of thinking about gay health issues.

¹⁹⁵. Helen Schietinger, interview with author, Washington, D.C., 26 September 1995.

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At Whitman-Walker Clinic, in Washington, DC, John Hannay became the first full-time employee when he was hired to manage the clinic's brand-new AIDS program in September 1983. Hannay's only experience with AIDS—far more than most people's at that point—was as a member of a small group of friends who were helping another friend, who had AIDS, when the man came from New York for weekly screenings at the National Institutes of Health, just outside of Washington.

When he started at the clinic, said Hannay, there were maybe a dozen AIDS cases in DC, and even fewer in the surrounding areas in Maryland and Virginia. "It took a while to realize it would be a serious problem," he recalled. "It was perceived as being concentrated in gay megacenters of the country, and DC was not perceived that way. There was a lot of difficulty getting people to see this was something urgent." The clinic tried futilely to draw attention to AIDS in newspaper ads. Finally, said Hannay, "When people began to get sick and dying, that got a lot more people to think."¹⁹⁶

Whitman-Walker sponsored the first community AIDS forum in Washington, on April 4, 1983. "We ran a few ads in the *Blade*," recalled Jim Graham, the clinic's board president at the time and its director from 1984 to 1998. "We had no idea whether or not people would be interested." By December of that year, the clinic's AIDS Evaluation Unit began to see patients. "There was no pretense of any treatment," said Graham, "and I wouldn't say it was a full diagnosis because there was no test." As if to underscore the fact that the fight against AIDS

¹⁹⁶. John Hannay, telephone interview with author, 16 July 1995.

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was a losing battle in those early years, he added, “We did have the ability to know what was a K.S. lesion.”¹⁹⁷

At a time when even medical diagnoses of AIDS were vague at best, no one could be precise about what, exactly, AIDS services ought to be. Certainly the District government didn’t know at the time. Jane Silver, who was the AIDS advisor to D.C.’s public health commission in 1983 and later the first director of the District’s AIDS office, said that Whitman-Walker took the lead in providing services to people with AIDS even as the city tried to figure out what hit it. Silver, who today is president of the New York-based Irene Diamond Fund, added, “I wish the government had taken more responsibility early on for requiring that the government services be on a par with Whitman-Walker Clinic.”¹⁹⁸

But as New York did with GMHC, the District of Columbia mostly left it to the gay community to address AIDS on its own. The outcome was too many horrific and heartbreaking stories like one Caitlin Ryan told me. Their theme was always the same: AIDS is gay people’s problem, not their elected leaders’.

Ryan, who today is a noted researcher on sexual minority youth at San Francisco State University, was the first director of Whitman-Walker’s AIDS program. She recalled receiving a phone call from the local prison telling her that a young man with AIDS was on his way to the clinic. She said, “This guy was probably twenty-two years old, very scared, his eyes were big as saucers, he had huge swollen lymph glands—serious lym-

¹⁹⁷. Jim Graham, interview with author, Washington, DC, 29 March 1995.

¹⁹⁸. Jane Silver, interview with author, Washington, DC, 13 March 1995.

VICTORY DEFERRED

phadenopathy. They assumed because he was gay that he had AIDS. He thought he had AIDS. All of his possessions were in a paper bag. They put him in a taxi and gave him cab fare. He showed up at the doorstep and just sat there with the stuff in a paper bag, with these huge tears rolling down his cheeks. He was just terrified. Of course we later found out that he didn't have AIDS; he had lymphadenopathy, and got treatment and care."¹⁹⁹ Like its federal overseers, the District government figured that any health problem of a gay person was a problem for gay people alone.

Established one year after Whitman-Walker, Chicago's Howard Brown Memorial Clinic also added AIDS services with the first appearances of AIDS in the city. Continuing its involvement in medical research that began with the hepatitis B studies in the seventies, Howard Brown in 1983 was chosen by the National Institutes of Health to participate in the Multicenter AIDS Cohort Study (MACS), the largest government-sponsored epidemiological study of how gay men's sexual practices might relate to the spread of HIV. "I thought we were in a very good position at Howard Brown, since we had just completed the hepatitis B study, had a cohort, and blood stored away," said David Ostrow, who became the MACS principal investigator at Howard Brown. "So the whole idea of the MACS was that if anybody had an idea what the vector was, we could go back to those blood samples and figure out the early curve of this in Chicago."²⁰⁰

¹⁹⁹. Caitlin Conor Ryan, interview with author, Washington, DC, 23 April 1995.

²⁰⁰. David G. Ostrow, MD, interview with author, Chicago, 3 June 1995.

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In other cities, gay health clinics organized AIDS services as freestanding agencies. Boston's premier AIDS service organization, for example, literally started out as a board committee of the Fenway Community Health Center, today known as Fenway Health, which was formed in 1971. Card-shop owner and long-time social activist Larry Kessler was a member of the committee from its first meeting, at the popular Back Bay gay bar, Buddies, in January 1983. In September of that year, Kessler was appointed as coordinator of the committee.

Like most other AIDS service organizations, AIDS Action Committee saw its first function as educating the community, offering what little information was available about the disease at the time. To raise money and awareness, the committee held its first fundraiser on March 29, 1983, a thirty-five-dollar-per-person dance at another gay bar off Copley Square called Chaps.

AIDS patients were referred to Fenway for medical care. And as it became clear that people with AIDS would need services, the committee created them. Kessler recalled, "There was a perceived need for a lot of specialized services, and a perceived need that unless we did it, nobody else would."²⁰¹

The Los Angeles Gay and Lesbian Community Services Center was also formed in 1971, emerging from the gay liberation movement that had begun to blossom in L.A. as early as the fifties, when pioneering activist Harry Hay formed the Matachine Society there. Eric Rofes, who became the center's director in the mid-eighties, explained in a 1995 interview, "It was founded by a group of people, including Morris Kite and Don Hill Heffner, who said they were trying to do political organizing among people who had been damaged by societal homopho-

²⁰¹. Larry Kessler, interview with author, Boston, 24 July 1995.

VICTORY DEFERRED

bia. They needed a place to bring people to heal while doing that work.”

By the time Rofes took charge, in 1985, the community center had already become the largest gay social service organization in the world, with a \$15 million budget, a staff of sixty, and a large building it owned. Among its many activities, the center ran an STD clinic, provided legal services, job training, and services for youth. “When the epidemic hit,” said Rofes, “the center stood in a frontline position.”²⁰²

The community center opened a hotline in its health clinic to provide information about AIDS to Los Angelenos. Soon enough, disagreement about how to run the hotline led the small group of people working on it to split from the center and form AIDS Project Los Angeles, which quickly became the second-largest AIDS service organization in the country (after GMHC in New York).

Bill Meisenheimer took advantage of a program offered by his employer, Xerox, to become a paid “volunteer” at APLA throughout 1983. He officially joined the staff on January 1, 1984, and within a month became the acting director of the fledgling agency. “I was not involved in the gay community, not in political organizing,” Meisenheimer told me. “I was just somebody driven by my fear.” He recalled that, although there was a groundswell of support from the community (even before it had the capacity to coordinate them, well over one thousand volunteers had come forward to help APLA), the political environment in Los Angeles was “a disaster.” Said Meisenheimer, “The county board of supervisors were worthless. They didn’t

²⁰². Eric Rofes, telephone interview with author, 7 July 1995.

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care about anything because of who [AIDS] was affecting. I would go and testify, and they would get up and walk out.”²⁰³

Meisenheimer’s successor as director of APLA was Paula Van Ness, who, as he had done, joined the organization as a volunteer. “I got a call from United Way,” recalled Van Ness, “and they said we have an organization that needs some help.” She was running a family-planning agency at the time. “Because you’re in the sex business,” they told her, “we thought of you.” They said it was an AIDS organization—not exactly a group most heterosexuals would have wanted to be associated with in 1985. As Van Ness recalled, “They were having a hard time getting the straight community involved. I said if they asked me to serve, I would serve on the board as a heterosexual woman. They said okay.”

So Van Ness joined the board, became its treasurer, and then was appointed executive director in 1985—just after APLA’s first “AIDS Walk,” and just before its first “Commitment to Life” event, which brought out Hollywood stars for one of their rare early appearances on behalf of AIDS. Both events benefited from the July 25, 1985, announcement that Rock Hudson had AIDS. APLA would certainly benefit from the cash and cachet of Tinseltown as the agency grew prolifically in the coming years.

When Van Ness went to APLA, the organization had a \$700,000 budget and seventeen staff members. By the time she left, only a year and a half later, APLA had exploded into a \$7 million organization with a full-time staff of eighty-two. “It really was on a very fast climb,” she said, “and quite remarkable that we did as well as we did to build the organization, expand

²⁰³. Bill Meisenheimer, telephone interview with author, 6 June 1995.

VICTORY DEFERRED

services to deal with what then felt like a crush of new cases, and meanwhile build the board. It was a pretty remarkable time.”²⁰⁴

Like its counterparts in New York, San Francisco, Boston, Chicago, and Washington, APLA’s growth and success made it a source of “how-to” information for those in other areas of the country who were interested in starting an organization to serve their own increasing numbers of people with AIDS. In October 1985, Van Ness and the directors of the country’s biggest AIDS service organizations at the time decided to form a national association of community-based AIDS providers. Based in Washington, DC, the National AIDS Network was created to be a kind of clearinghouse of technical assistance for new AIDS organizations across the country, a centralized conduit for sharing information on a national level.

The sharing of information was a lifeline sustaining the new AIDS organizations in the early years of the epidemic. They compared notes with one another, and contrasted their own experiences to those of mainstream organizations that operated with widespread support—including government funding—and the good will of their communities.

The social stigma attached to AIDS might have held back people more sensitive to it than the long-stigmatized gay men and lesbians who formed the early AIDS organizations. But the fact that they often were the only ones willing to provide care and support to people with AIDS meant that as the epidemic grew, the organizations they created to address it had to grow as well.

²⁰⁴. Paula Van Ness, interview with author, Washington, DC, 25 April 1995.

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Because AIDS service organizations felt they had to create a parallel system of health care and social services specifically for gay men, the most heavily affected group then and still, they tended to look to one another for direction, rather than to mainstream social service agencies that had experience they might extrapolate to AIDS. The frequent result was programs, and whole organizations, cobbled together by people with far more passion than managerial acumen, and services that were based more on the basis of hunches than on hard data that could permit the evaluation of their success or failure in traditional terms. At Whitman-Walker Clinic, Jim Graham said, “Everything we’ve learned, we’ve learned on the run. And we have learned it largely in isolation from mainstream models.” When the clinic wanted to create a housing program in 1984, for example, it sent people to the Shanti Project in San Francisco, rather than looking at housing programs in D.C. itself.²⁰⁵

After conferring with the “established” AIDS organizations in the early epicenter cities of New York, San Francisco, and Los Angeles, representatives from cities and towns where AIDS hadn’t yet become a major problem picked up useful ideas for services, as well as images of how the epidemic might soon look in their own hometowns.

Jim Holm, a cofounder of Seattle’s Northwest AIDS Foundation (known since its 2001 merger with the city’s Chicken Soup Brigade as Lifelong AIDS Alliance), described the lessons that he and others in the city’s gay community took from the “tutors” they brought to Seattle from New York and San Francisco. He said they provided “a snapshot of what faced us just months behind them.” Like San Francisco, Seattle’s gay community enjoyed an amiable relationship with the city government that would prove invaluable in shaping the city’s well-coordinated

²⁰⁵. Graham interview.

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response to the epidemic. As Holm put it, “Cooperation here between health officials in government and community members was rich and very productive. It was hard, but both sides stayed at the table.”²⁰⁶

One of the people at the table from the beginning was Bob Wood, a physician long active in Seattle gay politics and a member, in 1983, of the Northwest AIDS Foundation’s first board of directors. Wood recalled that gay AIDS groups in other cities, New York in particular, were seeking contributions around the country to support their efforts to provide AIDS services at a time when they had no financial support from any level of government.

But the “snapshots” of the epidemic in New York and San Francisco convinced the community in Seattle that it was best to focus its attention and resources locally. Wood recalled, “People put two and two together, and said ‘Why should we give money to New York, when it’s probably going to hit us, too? We need to develop our own response mechanism for it.’”

By the middle of 1983, not only had gay people formed the Northwest AIDS Foundation, but they were also working with the public health department to lobby the Seattle-King County council for a project within the health department to focus on AIDS. Wood became—and remained, until his 2010 retirement—the director of that program.²⁰⁷

When Bea Kalleigh was hired in August 1985 to be the Northwest AIDS Foundation’s first executive director, the orga-

²⁰⁶. James Holm, letter to the author, 29 August 1994.

²⁰⁷. Robert W. Wood, MD, interview with author, Washington, DC, 28 September 1995.

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nization had a budget of \$28,000. During Kalleigh's four-year tenure, that budget increased more than fifty times to \$1.5 million. After leaving the foundation, she took a yearlong, mid-career sabbatical at Harvard Business School. In a leadership class, Kalleigh recalled studying a case that examined the reasons companies go under. Without a forward-looking plan and with too-rapid growth, an organization risked imploding. Said Kalleigh, "I remember thinking that we grew at the AIDS foundation way more than the rate of growth they were talking about, because of the urgency in the community that people brought to it. We ended up starting new services, and the need actually grew faster than we did. There were always new people delivering new services—and the community always wanted more."²⁰⁸

During her one-year stint as the Clinton administration's first AIDS "czar," Kristine Gebbie from 1993 to 1994 visited AIDS organizations throughout the country. Gebbie recalled observing a kind of delay in the way the AIDS epidemic manifested itself on the coasts and in the heartland, and in the mobilization of local communities to deal with it. "The middle-of-the-country gay groups are today where the coastal groups were in 1985 to 1987," she told me in 1995. "I traveled quite a bit in my year, and when I went to Montana, for example, I thought I was in a time warp. I experienced the same thing in the Midwest and parts of the South. This drove home to me over and over again how many little epidemics we're really fighting, and that to think that all gay groups are like the coastal groups is a real error."²⁰⁹

²⁰⁸. Bea Kalleigh, telephone interview with author, 5 October 1995.

²⁰⁹. Kristine Gebbie, interview with author, Washington, D.C., 15 March 1995.

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To get a picture of the “time warp” Gebbie described, I talked to two gay men involved in AIDS services in America’s middle states. When AIDS first appeared in Oklahoma City, in 1983, psychiatrist Larry Prater began stirring up controversy with the state government over his safe-sex posters and a large billboard towering over the small AIDS service organization he helped to found. One side of the billboard said, “Masturbation education: Do your homework” (in response to a flap over then-Surgeon General Joycelyn Elders’ comments on the subject), while the other side encouraged condom use. Said Prater, “I’m sure that’s the first time the words ‘masturbation’ and ‘condoms’ were seen in public—let alone in eighteen-inch-tall letters!”

When not shaking things up, Prater was one of the few openly gay physicians in the conservative state to provide AIDS services to the gay men in the area who accounted for virtually all the local AIDS cases. I visited him in early 1993 at the Triangle Club, a converted automobile showroom located on the same small strip as the city’s gay bars and bookstore. Triangle offered antibody testing after it became available in 1985. It also ran a food bank, operated a certified day treatment center for substance abuse, and provided limited HIV treatment services—“a big, big money loser,” said Prater.

Prater told me in a later interview that in an area like Oklahoma, the Triangle Club’s anonymous HIV testing policy and confidential treatment was essential to bring in people at risk for testing, and to provide treatment to the infected. “For many, many gays in Oklahoma, their families do not know about them,” said Prater. “If anything, having HIV is an even touchier issue for a lot of these guys than being gay, and they’re not going to tell their families that they have HIV if they haven’t told them that they’re gay.” He added, “Some families in Oklahoma

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would rather have no child at all than have a gay or lesbian child.”

Other families, usually “good Christian” ones, simply disown the gay children they do have, and often in rural areas where there are few gay community resources they wind up at an AIDS organization like the Triangle Club. More often than not, the organizations were connected to the local gay community. To illustrate, Prater recounted a recent example. “Last Monday night,” he said in 1995, “we had this cute young couple, male and female, come in for testing. It turned out they were brother and sister, from Idaho. I asked them how they wound up in Oklahoma City, because more people leave Oklahoma than come there. They left because their family banished them to the hinterlands. These were the only two children of the family, and one’s gay and the other is lesbian. I think this was more than the family could handle—they’re very religious—and they just sent them away. They said they have each other. They were each about twenty-five, and had been in Oklahoma about three years.”²¹⁰

Arkansas native Ron Thompson’s first encounter with the epidemic was when one of his friends from college called to tell him he had AIDS. “I went ‘Wow!’” he said. “This is real.” The young man was someone Thompson “had done a lot of running around with, and took a couple of boyfriends from.” Thompson hooked up with local efforts in his hometown of Little Rock.

After volunteering and serving on various boards, Thompson began to use his training as a social worker to provide AIDS education to mental health clinicians and laypeople alike throughout the state. I asked Thompson to describe the people

²¹⁰. Larry Prater, MD, interview with author, Miami Beach, 20 May 1995.

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in then-President Clinton's own home state who had gotten involved with organizing local service groups. "A good chunk of them are gay people," he said. "But a lot of families and parents started stuff because their gay son is dying or has died." As it was throughout most of America, Thompson said that in Arkansas, "In most cases it is gay individuals who started AIDS organizations." But, he added, "You find a lot of little old ladies saying, 'Wake up world!'"²¹¹

It isn't hard to understand how small towns and rural areas could ignore the epidemic until AIDS turned up in their own backyards. They simply figured it was a problem for city folks. It is more difficult to understand why the early AIDS organizations in hard-hit cities often ignored gay men of color affected by the disease living in their own city.

George Bellinger, Jr., a longtime Black gay activist, was an early volunteer at D.C.'s Whitman-Walker Clinic in 1983, when it began to provide AIDS education and services. Despite his own presence, he recalled, no one seemed to want to know about the Black gay men who were becoming infected and developing AIDS even early in the epidemic. But this was nothing Bellinger hadn't already encountered in gay bars. An assumption on the part of many white gay men that gayness implies membership in the Caucasian race (and the male sex), meant they didn't consider a shared sexual orientation to be grounds enough for equal representation in the community institutions they created. Said Bellinger, "When I went to a bar, I didn't see myself reflected." Likewise, he added, the messages put out by early AIDS organizations "were always geared to white gay

²¹¹. Ronald Thompson, telephone interview with author, 15 July 1995.

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men who went to the gym, or lived in the gay ghettos. They did not talk to us.”²¹²

Many white gay men emigrate to the nation’s big cities from the small towns in which so many of them grow up because they feel they can live more comfortably in a more tolerant and diverse urban environment. Gay ghettos have flourished in places like New York’s Greenwich Village and Chelsea, San Francisco’s Castro district, Capitol Hill in Seattle, Houston’s Montrose neighborhood, the West Hollywood section of Los Angeles, Chicago’s New Town, the South End of Boston, and the Dupont Circle (and more recently, Shaw) neighborhoods in Washington, DC. Not surprisingly, these neighborhoods were the first and hardest hit by AIDS, as well as the locations of the earliest AIDS organizations.

In contrast, far fewer Black, Hispanic, and Asian gay men—as well as working-class white gay men—uproot themselves from the neighborhoods in which they grow up. As a result, they frequently lead double lives: ostensibly heterosexual while among their families and neighbors, possibly even married to women—but engaging in sex with other men in furtive encounters, often referred to as the “down low” or “DL,” or even ongoing same-sex relationships.

Because homosexuality is so harshly condemned among many people of color, these men feel driven to hide their sexual orientation at home. But the gay community—most visibly comprised of white men and women—reflects the racial insensitivities and imbalances of the broader society. Unfortunately, this means that gay people of color often don’t find a welcoming embrace in that quarter, either. The result is a dual membership

²¹². George Bellinger, Jr., interview with author, New York City, 2 March 1995.

VICTORY DEFERRED

in the individuals' racial or ethnic community and the gay community, and loyalties often sharply divided between the two.

It wasn't just the white gay community that overlooked the AIDS concerns of people of color. In the hardest-hit Black community, for example, the early attitude toward AIDS was, "It's a white gay thing." They saw homosexuality as a "disease" of white people, and since AIDS was viewed by just about everyone as a gay disease, even Black gay men at first dismissed it as irrelevant. They were unaware in the early years of how disproportionately hard AIDS was already hitting their own.

As astonishing as it seems, people in the Black community fifteen years into the AIDS epidemic were still saying, as did a 1996 op-ed article by African-American *Washington Post* columnist William Raspberry, "AIDS is becoming a Black disease."²¹³ Unfortunately for far too many in the community, it had become a disease heavily affecting Blacks at least a decade before Raspberry's epiphany.

Fortunately for all people of color, gay and straight, there were gay people willing to speak out about AIDS in their communities. Like their white gay brothers, these people realized that lives were on the line, and they decided that the tacit agreement that kept them hidden conveniently away in the community's closets was no longer binding. The added weight of fear and grief they were carrying, as they saw friends getting sick and dying amid the denials and outright lies about the real nature of their illness, made the masks they'd hidden behind far too heavy to hold up. Stepping out of their closets and casting off their shame, "Black gay men were the leaders in bringing

²¹³. William Raspberry, "AIDS is Becoming a Black Disease," *Washington Post* (11 October 1996), A25.

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this disease to the attention of the Black leadership,” as Gil Gerald put it.²¹⁴

Reverend Carl Bean was one of the first to speak out. A successful gospel singer who had become a minister and founded a Christian denomination chiefly for Black gay men and women, Bean became known nationally for bearing witness to the impact that AIDS was having on people of color, particularly gay men. When he began traversing the city of Los Angeles by bus and subway to minister to Black men with AIDS in the city’s hospitals, Bean said, “Even with the virus and T-cell counts, what I was hearing most was ‘Would you tell my family that I’m homosexual, or would you be here with me when I tell them?’ The other big part of it was ‘Am I going to hell?’”

It was clear to Bean that if Black gay men with AIDS were going to get the care they needed, something had to be done to disperse the cloud of denial and opprobrium around homosexuality and AIDS that had enveloped the Black community. He recalled that he used to open his speeches to Black church groups by saying, “Now, you all *know* who we are. You all *know* who’s on the piano. You all *know* who’s at the organ. Everybody here *knows* who’s leading that song on Sunday that makes you happy.” He added, “The room would always fall apart with laughter, and it would always take the tension out of the room and everyone could relax and they’d start asking real questions.”

Bean realized that his work needed to include starting an AIDS organization in the Black community. “I always knew I had to go home,” he said. In 1985, Bean formed the Minority AIDS Project as an outreach of his Unity Fellowship Church in South

²¹⁴. Gil Gerald, telephone interview with author, 25 August 1995.

VICTORY DEFERRED

Central Los Angeles—an area that in the early nineties would symbolize the country's festering racial wounds when riots broke out there after the acquittal of city police officers accused of beating Black motorist Rodney King. "Being Black and gay," said Bean, "and having been Black and gay in the community, I also knew the only voice that was going to deal with the issue was going to be a Black homosexual who had in fact had the experience of being very openly homosexual in the community."

Other Black gay men told Bean it couldn't be done. He recalled, "Blacks said no, you can't do it." As for Bean's idea that the Minority AIDS Project would be part of his church's ministry, he said the others' reaction was "Jesus and gay and Black and church? No!" Bean persisted. "I said yes, it will happen, because all of that is alive in me, and I'm real. I am Black, I am Christian, I am gay, and I'm a part of the Black church."

The other men were intransigent. Bean recalled them saying, "No way, honey. You'd better look for a piece of property up there on Santa Monica Boulevard." Bean held fast. "I said no. To be openly gay on Santa Monica, if you're Black, is not openly gay. Until you're openly gay on Crenshaw, in South Central, you are not openly gay. That's how I feel about that. You're not really open until you're open in the 'hood."

Carl Bean's simple belief in the power of integrity would go a long way toward winning the Black community's confidence in the Minority AIDS Project. When the Brotherhood Crusade, a project of the Black United Front of LA, made the first-ever donation to Minority AIDS Project, Bean recalled the group's leader saying to him, "You know, my wife and I have gay friends. We go to their house for Christmas, and they never say they're homosexual, they never say they're lovers. Everyone knows they are." The man added, "We'll gladly give you money, but you're the first homosexual Black who's stood here in the

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community and said you're homosexual. Yes, we'll help you with this AIDS thing."²¹⁵

When gay men spoke out honestly, and little old ladies said "Wake up, world!" others also came forward because they knew that, as Patti Austin's AIDS anthem puts it, "We're all in this together."

²¹⁵. Rev. Carl Bean, interview with author, Washington, DC, 16. November 1995.

TEN

The AIDS epidemic broke out not long after Ernesto Hinojos finished a degree in public health. As a gay man, Hinojos wanted to become involved with AIDS because the disease was striking his own community. Marc Conant offered Hinojos a position in his new KS Clinic. Years of AIDS work later and a continent away, Hinojos recalled in a 1995 interview in New York his first experience of seeing a KS patient at the clinic in San Francisco. "This was such a disfiguring disease," he said. "I just cried and cried. But that was out of my own fear, my own sense that that's a brother, and that's somebody who's depending on me as his only link. So I rubbed my eyes and walked back into the room. I said if you'd like, I could walk you over to the radiation unit, and I'll sit with you if you'd like. If you don't have anybody here, I don't mind doing that."

Of course the young man had no one there with him. Likely his family were far from San Francisco, that he'd been one of the thousands of gay men who'd fled a small hometown and flooded the city in the seventies. In the early years, even gay men were wary of other gay men with AIDS because of the lack of information about the disease's cause, downright fear, and the self-protective belief that somehow those men had brought it on themselves. Gay friends too often fell away when AIDS was diagnosed.

So here was this young man, with a confounding and hideous disease, alone in a medical clinic—in the city where he thought, as had so many other men like him, he would find freedom, his very own pot of gold. It's highly unlikely he ex-

VICTORY DEFERRED

pected to find a horrific and lonely death at the end of his particular rainbow.

“That would be really nice,” said the young man. “I’d really like that.”²¹⁶

As Hinojos had been to this early AIDS patient, gay people and organizations throughout the country were one another’s only link to information about the epidemic, the government’s faltering response to it, and the political implications of it all. The social and political contacts established in the gay community nationally during the seventies now became invaluable connections as everyone puzzled out what was happening and how to respond.

Telephone lines burned up with inquiries and news from city to city, coast to coast, as the newly formed AIDS organizations—typically with a handful of underpaid employees, a group of volunteers offering their energy, and no one on staff capable of fully channeling it—shared information with one another. Many of those leading the groups had been local gay political activists in the seventies. Few of them had the kind of management and fundraising skills that would be needed in the coming years as the service organizations grew in tandem with the burgeoning epidemic.

As would be proven repeatedly and in a variety of contexts in the AIDS epidemic, information truly was power. And a community painfully aware of its own history of powerlessness insisted upon receiving scientific information as it became available.

²¹⁶. Ernesto Hinojos, interview with author, New York City, 2 March 1995.

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The nascent AIDS organizations assumed the role of translators, frequently through the volunteered services of gay physicians and other medical professionals, digesting and disseminating the latest scientific information to others in the community. This information sharing would serve as the catalyst for the community's ability to mount a political response to the epidemic in the coming years.

It was only natural that an information hotline would be the first AIDS service ever created, as it was at GMHC and many other AIDS service organizations. Rodger McFarlane's personal answering service that became GMHC's first hotline; the single phone line at the KS Foundation that Cleve Jones said "never stopped ringing"; the hotline at the Los Angeles Gay and Lesbian Center that became AIDS Project Los Angeles—each of them, like so many others in cities and small towns across America, represented an effort to provide information, prevent panic, and promote a feeling of "connection" to the community. They provided life-links for individuals diagnosed with or at risk for AIDS, and they became the nerve centers for a gay community fearful of the medical and political uncertainties of AIDS.

From the one hundred calls to its hotline the first night it operated, GMHC today fields upward of thirty-five thousand calls and Internet inquiries. When AIDS is in the news, the number increases. When Magic Johnson announced in 1991 that he was HIV-positive, for example, GMHC logged seventy-eight hundred calls within a month.

Before leaving GMHC in 1997 to pursue a counseling career, Bruce Patterson was director of the agency's hotline for nearly twelve years—the longest-serving staff member at the world's oldest AIDS organization. Patterson was volunteering at GMHC before leaving his job in the film business to become the assistant to GMHC's hotline coordinator in February 1986. He

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was offered, and happily accepted, a salary that was half of what he gave up. “I had to go back to living again like a poor student—spaghetti every night,” Patterson recalled. “Plus I was trying to support a lover who had AIDS and wasn’t working. I don’t know how I did it!” Patterson is clear, though, about why he did it. He said, “I think one of the reasons I got involved in this work was that it was a way to help the community, which really needed help because no one else was helping us back then.”²¹⁷

When the federal government finally decided to create a national hotline to make AIDS information widely available, the CDC sent representatives to the National Gay Task Force, then based in New York City. Ginny Apuzzo, the task force director at the time, recalled that GMHC in 1983 had given the group money to create a hotline. Apuzzo turned the task force’s violence crisis-line into the very first national AIDS hotline in the country. She recalled, “When PHS [Public Health Service] finally agreed to establish a national hotline out of New York, they came to NGTF’s offices in New York, on Fifth Avenue, and sat there and watched the way we did the job.”²¹⁸

Most other AIDS services were created because having the disease typically meant the loss of a job and the ability to live independently. Psychologist Lewis Katoff, who worked for years at GMHC until his own death from AIDS, explained in a *Primary Care* article that most community-based AIDS services attempted to address a limitation or problem—whether physical, social, or psychological—that resulted from the illness. He not-

²¹⁷. Bruce Patterson, interview with author, New York City, 2 March 1995.

²¹⁸. Virginia Apuzzo, telephone interview with author, 8 August 1995.

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ed that the mix of volunteers and professionally trained staff used in providing AIDS services had several advantages, including cost effectiveness, empowerment, flexibility, quality of attention, accessibility, and cultural sensitivity.²¹⁹

The main goal of all AIDS services was always to keep people out of the hospital and functioning as independently and for as long as possible. But because AIDS was a progressively debilitating disease, the particular types of services needed varied over the course of the illness.

Bea Kalleigh said that people organizing services recognized early on that “health care was extremely necessary, but health care alone was not the whole story in a healthy life.” She explained, “With AIDS, people’s physical as well as financial and emotional situation changed, sometimes regularly and precipitously.” Supportive services that had been designed for other groups of people—the elderly or the chronically mentally ill, for example—weren’t intended for young gay men with a disease that could fluctuate wildly, sometimes incapacitating them, and other times making hardly a mark in their day-to-day functioning.

The earliest services for people with AIDS were designed to assist with the bare necessities of life—shelter and food. In December 1982, the Shanti Project contracted with the San Francisco Department of Public Health to create the world’s first housing program for people with AIDS, which was to be replicated throughout the country. Helen Schietinger, the program’s first director, explained that Shanti rented houses and apartments, furnished them through volunteer donations, and then

²¹⁹. Lewis Katoff, “Community-Based Services for People with AIDS,” *Primary Care* 19 (March 1992): 231–43.

VICTORY DEFERRED

rented rooms to people who were screened to keep out those who were active drug users or acutely ill.

Schietinger noted how novel the program was, created because young gay men with AIDS were not seen as viable residents of geriatric nursing homes. “We were making things up as we went along,” she said.²²⁰ As it had been for Washington’s Whitman-Walker Clinic, the Shanti program served as a model for a number of other AIDS service organizations across the country.

When Ruth Brinker’s next-door neighbor in San Francisco, a gay man, developed AIDS in 1984, the widowed lady was startled to learn that because he was too weak to prepare his own meals, and friends were too busy to help, the man often went without food. A volunteer with Meals on Wheels, Brinker realized that “there was absolutely no way that people with AIDS could have meals brought to them unless they were over sixty years old—usually not the case for PWAs—and could qualify for Meals on Wheels.”

In the fall of 1985, Brinker decided “no one who was ill should have to go through anything like that.” After putting in a full day at Meals on Wheels, she began cooking up stews, pot roasts, and fish for seven people with AIDS. With the help of a few volunteers she delivered the meals, often going into the city’s Tenderloin district, where people with AIDS who had lost everything because of their illness were forced to live in seedy hotels.

Brinker talked Trinity Episcopal Church into letting her use its kitchen. Without funding, infrastructure, or fanfare, Project

²²⁰. Schietinger interview.

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Open Hand was born. When word about the project got out, volunteers by the score came in to help.

Within three years, Project Open Hand was serving four hundred fifty people with AIDS two meals a day through the efforts of a part-time staff of seventeen, numerous volunteers to deliver the meals, and even well-known chefs who would occasionally take a turn in the kitchen.

When Open Hand began delivering meals, Brinker noted that many people, suffering from both AIDS and malnutrition, could barely walk to the door to let in the volunteers bringing their food. Thanks to Open Hand, that happened less often. Brinker said, "I use only fresh produce, the best ingredients I can find, and no preservatives. I believe that giving really good, wholesome food to people *before* they are debilitated helps them stay healthier longer and enjoy life more."

By 1988, Brinker was using her own energy to help other communities around the country begin food programs like Project Open Hand. In 1989, the project published *The Open Hand Cookbook*, a collection of complete menus prepared by prominent California chefs. In keeping with the neighborly spirit that led Ruth Brinker to begin cooking for people with AIDS, the book is subtitled, "Great Chefs Cook for Friends."

When she started Project Open Hand, Brinker said, "I just wanted to feed a few people." Asked at the time whether preparing nine hundred meals a day for four hundred fifty people with AIDS was an overwhelming task, Brinker said, "Not when you think of the number of PWAs Washington tells us we're go-

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ing to be serving.”²²¹ When Ruth Brinker began Project Open Hand in 1985, “only” 22,996 Americans had been diagnosed with AIDS. Within a decade, well over half a million people in this country alone would be diagnosed with or already dead from AIDS.²²²

After the basics of shelter and food were satisfied, the psychological well being of people with AIDS was made a high priority. The physical insult of the disease, the stigma attached to having a deadly sexually transmitted disease, the fear of death, added to a lifetime of psychological injury, made gay men with AIDS extremely susceptible to major depression and even suicide.

Volunteers from the Shanti Project, trained in working with death, dying, and bereavement, were the first to offer support groups to people diagnosed with AIDS. Support groups soon became a standard part of the treatment of people with AIDS throughout the country. San Francisco psychologist Steve Morin noted in a 1984 *American Psychologist* article on the subject, “The physical contact in support groups is of great importance to people with AIDS, who may not get much physical comfort elsewhere due to people’s unjustified and ill-informed fears of casual contagion. The group also helps people express their anger and resentment as a result of having lost friends,

²²¹. Ann Thérèse Carlozza, “Ruth Brinker’s Spirit Sustains ‘Open Hand,’” *The NAN Monitor* (Washington, DC: National AIDS Network, Fall 1988).

²²². Centers for Disease Control, *HIV/AIDS Surveillance Report* 8 June 1996.

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lovers, and homes, and at being asked to leave bars, restaurants, and even juries.”²²³

To help people with AIDS take control of their lives and function as normally as possible, Shanti created another novel service, the volunteer buddy program. “Buddies” helped out with practical matters, such as grocery shopping, cleaning, and cooking. Typically they weren’t expected to provide emotional support, an area that belonged to other volunteers. But it’s probably impossible to come as a stranger into someone’s home, help him in his efforts to retain his dignity and functioning, and not become a friend.

In many cases, gay men literally had no one to count on. Families were often far away, possibly alienated. Good-time friends stopped calling. Fortunately, there were many “buddies” in the community—people who, though probably also living far from their own families and perhaps their pasts, understood the importance of connection to others who cared.

In addition to pulling together a group of doctors and community activists to advise the city on how to handle AIDS, Boston’s liaison to the gay community, Brian McNaught, wrote a regular column for the local gay newspaper, called “A Disturbed Peace.” He authored a book of the same name, in which he explored the experience of being a believing but disillusioned Catholic. And he trained to be an AIDS buddy.

“For a lot of us,” McNaught told me, “being a buddy was completely consistent with our image of what it meant to be a person of faith. The Gospel said ‘I was naked and you clothed

²²³. Stephen F. Morin, Kenneth A. Charles, Alan K. Malyon, “The Psychological Impact of AIDS on Gay Men,” *American Psychologist* 39 (November 1984): 1288–93.

VICTORY DEFERRED

me. I was sick, and you visited me.' Francis of Assisi talked about 'Make me an instrument of your peace,' and 'Where there is despair let me bring hope.' All of that plays heavily into my feeling about our responsibility to each other."²²⁴

"All of that" figured prominently in the belief of many gay men and those who cared about them that, as W. H. Auden put it, "We must love one another or die."²²⁵

²²⁴. Brian McNaught, telephone interview with author, 25 August 1995.

²²⁵. W. H. Auden, "September 1, 1939." Larry Kramer derived the title of his play, *The Normal Heart*, from this poem, and its last line, "We must love one another or die" is the title of an anthology about Kramer, edited by Lawrence D. Mass.

ELEVEN

For Peter Lee, a job that seemed “abstract” and a growing awareness of AIDS led him in 1984 to volunteer as a buddy at Whitman-Walker Clinic. He told me he’d been “transformed” by working with an AIDS patient at the National Institutes of Health. “The immediacy of AIDS in terms of my personal life swamped anything else I could do,” said Lee. “So I began looking around for anything else I might do directly in relationship to AIDS.” Which is what took Lee to Baltimore’s HERO, the Health Education Resources Organization, an AIDS service group established by the city’s gay community.

From there he moved to a position with the National AIDS Network, the Washington-based “trade association” of local AIDS service organizations. Through his volunteer and then compensated work on AIDS, Lee, like many others, was truly transformed into what became known as an AIDS professional, one whose full-time work revolves around some aspect of AIDS. Today Lee is a lawyer working on health care policy issues with the Pacific Business Group on Health, in San Francisco.²²⁶

Others came into AIDS services as professionals whose particular skills were important to meeting the various needs of people with AIDS. In the early years especially, before there was an Americans with Disabilities Act to protect them, people

²²⁶. Peter X. Lee, telephone interview with author, 2 September 1995.

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with AIDS often were fired from jobs, evicted from their homes, discriminated against, and abused in countless ways.

Houston lawyer John Paul Barnich was someone who put his considerable legal skills to good use on behalf of people with AIDS. When Barnich was studying comparative religion in India on the Fulbright grant he'd won halfway through law school, he visited one of Mother Teresa's homes for the poor. "I had what I guess is as close to a religious experience as I ever hope to have," Barnich told me. "On the wall, someone had painted, 'God is love in action.' I said, 'This is a concept of God I can deal with—translating caring into some sort of action.'" Not long after the former schoolteacher finished law school, what Barnich called "the great plague" hit, and, with it, "a great opportunity to get involved and do things."

Barnich joined the board of AIDS Foundation Houston in 1984, two years after the organization's founding. "I was present the night we became a social service foundation," he recalled. "This PWA showed up, didn't have money, and no place to stay. We chipped in and gave him money, and found him a place." Barnich's usual role with the foundation and its clients was as a legal protector of people with AIDS in Houston. Having lost his own lover to AIDS in 1994, Barnich said, "It's very, very personal to me, the fight against AIDS. I tend to react to people being discriminated against based on their HIV status like a wounded mother grizzly protecting her cubs. I have no mercy if people choose to be intentionally discriminatory. I see my job as making it as costly as possible for them."

In fact, Barnich has been involved in several prominent AIDS discrimination cases, including a highly publicized one involving unethical behavior by television reporters who fomented a sensational AIDS story so they could cover it. With the colorful storytelling characteristic of his adopted state, Bar-

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nich regaled me with one case after another. The case of Fabian Bridges stands out.

Bridges was a thirty-year-old Black gay man with what at the time was known as “full-blown” AIDS, who came to Houston, and into Barnich’s life, in late 1985. After a couple of public TV reporters talked to the board of AIDS Foundation Houston about doing a “humane” story on AIDS, they reappeared with Bridges. They were actually following him around the country. Barnich explained, “Every place that Fabian went they would report to health departments that there was this young male prostitute with AIDS who was having sex.” Barnich said that Bridges told him the reporters had given him money to eat and stay in shabby hotels while they reported on the “story.”

When they landed in Houston, Barnich and a local gay activist met with Bridges in a gay coffeeshop. “The media were like sharks circling the coffeeshop,” Barnich recalled. S. R. Andrews, an officer from the vice division of Houston’s police department, told Barnich to get Bridges off the street. Barnich had other plans. “I suggested to Officer Andrews that he not waste his time, that I’d be down there with a writ of habeas corpus, or the guy’s bail, before they even got him arrested.”

Bridges agreed—initially—to commit himself to one of the county hospitals. After a few days, though, he became restless and wanted out. Eluding the assembled news media by leaving the hospital through underground tunnels, Barnich said he “snatched up” and “stashed” Bridges at his own house.²²⁷

Most people who have provided AIDS services have had far less dramatic experiences than Barnich’s involvement with

²²⁷. John Paul Barnich, telephone interview with author, 1 October 1995.

VICTORY DEFERRED

Fabian Bridges. They have quietly gone about the business of assisting people with HIV however they needed to be helped. Although AIDS services, like the epidemic itself, typically have included the same basic features, communities across the country have shaded them with local color to reflect their particular needs. The case of Provincetown, Massachusetts, is one example.

In a 1995 interview at her home in Provincetown, Alice Foley vividly recalled when AIDS hit P-town. When a man asked her in 1981 to visit a sick friend, Foley was shocked at what she found. "I still remember walking in and seeing the young man," she said. "He was covered in what I know now to be Kaposi's. I never saw anything like that in my life. It looked like someone took a paintbrush and shook purple paint at him."

Foley had just begun to hear about "gay cancer," but she was unprepared for this. "He was dehydrated," she recalled. "He was very, very sick. He didn't have any help, and died within a week. That really sent up a red flag that this was a serious situation."

The next AIDS case in P-town was a referral from Massachusetts General Hospital, in Boston. A young gay man had driven to Boston from his home in Colorado, because the city's many hospitals and three major medical schools give it the reputation of being a medical "mecca." After being diagnosed with an AIDS-related infection, and having everything stolen from his car during the two weeks he spent in the hospital, the man was referred by a social worker to P-town because there was a visible gay community there. "This was in November, which is a terrible time to come here in you have no work," said Foley. She got him on the senior Meals on Wheels program.

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After Foley bumped into Preston Babbit, a fellow Business Guild board member, as they both sneaked into the winter apartment where the young man was staying, the two pulled together a group of about five people—including a realtor, a guesthouse owner, and a bartender—to discuss the situation and figure out how to deal with it. When AIDS finally had a formal name, the group took a name as well: the Provincetown AIDS Support Group (known today as the AIDS Support Group of Cape Cod). At the time, P-town had only two or three people who were sick.

Because P-town is isolated, particularly in winter, and many year-round residents have little money and few have cars, transportation was the first, because most-needed, AIDS service there—as it has been in rural areas throughout the country. The AIDS Support Group enlisted volunteers with cars who could help drive clients to doctors and hospitals in Boston, more than two hours away. Volunteer drivers rented cars because none of them had a car deemed safe enough.

The \$480 from a fundraiser at Alice's Café—"We thought we were very, very wealthy," said Foley—didn't go far. At ninety dollars per trip, the group realized the service wouldn't work. It wasn't until 1986, four years after the group formed, that they finally had a Ford Escort station wagon donated.

The second service created in Provincetown was home care. If the goal of AIDS services everywhere was to keep people out of the hospital as long as possible, in P-town it was simply a necessity because of the town's remote location. Said Foley, "From here, if you were in the hospital in Boston, friends couldn't really visit you because of transportation. They'd have to get there on the bus."

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More than a decade after she led the formation of the Provincetown AIDS Support Group, and a few months after her departure as its only director to that point, Foley looked back with hard-won pride on the group's success. "From the beginning we were fortunate in having a tremendous sense of volunteerism in the community," she said.

By the time of our interview, nearly four hundred people already had died from AIDS in the small community. But Foley emphasized that only a dozen of them had died in the hospital, while "the rest died at home."²²⁸ As the hometown of choice for so many gay men and lesbians who truly feel free in Provincetown, "death at home" has had more than usual significance.

In Provincetown I also interviewed a physician who had just moved there from another small New England town—my own hometown, Norwich, Connecticut. I first saw Larry Millhofer's name in a front-page article about him in the *Norwich Bulletin* in late 1994. The article described Millhofer's experience as a gay physician (actually a gerontologist) in Norwich, and mentioned his role in organizing the local AIDS group. I was intrigued to know about his experiences in Norwich, where Millhofer had practiced since completing his medical residency in San Francisco in 1978.

"It was fairly known in the community I was a gay physician," he said. "But a lot of gay men didn't come to me for fear of being labeled gay." Millhofer's first AIDS patient was John, an elementary school janitor. Despite AIDS-related memory problems and wasting syndrome, John was supporting his mother, lover, and grandfather, who lived with him in a duplex house. After the landlord began to suspect that something was

²²⁸. Alice Foley, interview with author, Provincetown, Mass., 30 July 1995.

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going on, Millhofer got a call from a *Bulletin* reporter. Millhofer had put on John's death certificate "AIDS dementia complex," and it was, technically, a matter of public record.

The reporter was planning to write an article about the situation, until Millhofer threatened to sue the paper. The good doctor said, "Even though this man was the janitor, I think his working in the elementary school had the potential for it to be blown out of proportion." Noting that public hysteria was common at the time, Millhofer added, "I think this was after the Rays were burned out in Florida," referring to the family whose home was torched because their hemophiliac boys were infected with HIV.²²⁹

In the early years of the epidemic, most people with AIDS were cared for by a small number of gay doctors like Millhofer. Some of them, like David Ostrow, had already been involved with gay health issues for years. Others became AIDS specialists because so many of their gay male patients were showing up with exotic HIV-related problems.

Still other doctors, who were not gay, refused to treat gay men, with or without HIV. As Millhofer put it, "A lot of physicians actively avoided learning about how to treat AIDS-related illnesses so they could say they were ignorant about it. A lot of people avoided becoming involved."²³⁰

Considering the way so many physicians avoided AIDS, it's interesting to note that all the gay doctors interviewed for this book have said they still would have become involved with car-

²²⁹. Lawrence Millhofer, MD, interview with author, Provincetown, Mass., 30 July 1995.

²³⁰. Millhofer interview.

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ing for AIDS patients even if the patients weren't gay men. Ken Mayer, for example, said, "It's actually easier for those of us who have a professional calling, because if AIDS wasn't a gay problem tomorrow, I'd still be interested because my interest is social medicine. I wouldn't be totally dispassionate even if I was only taking care of women."²³¹

Donald Abrams told me he went "kicking and screaming" from his job at Marc Conant's KS Clinic to the AIDS clinic at San Francisco General Hospital. As one of the handful of physicians who were "in the right place at the right time" when AIDS appeared, Abrams was recruited by Paul Volberding, the clinic's director, who was in charge of caring for patients with KS and malignancies. Volberding and Abrams specialized in the pre-AIDS stage of illness formerly called AIDS-Related Complex (ARC), and Connie Wofsy was in charge of treating opportunistic infections. Wofsy died of breast cancer in June 1996.

The decaying hospital with graffiti-sprayed elevators was not the ideal of either Abrams or his gay patients. Said Abrams, "My patients were all educated, well-to-do, with insurance and high socioeconomic status. I didn't appreciate that they had to be transferred across the city for treatment at the county hospital."²³² But even the KS Clinic, like physicians around the city, had begun to send patients to San Francisco General for treatment. Soon the hospital's reputation for excellent AIDS care would spread worldwide.

²³¹. Kenneth Mayer, MD, interview with author, Boston, 25 July 1995.

²³². Donald I. Abrams, MD, telephone interview with author, 17 July 1995.

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Before the AIDS epidemic, “you were hard-pressed to find a gay man in San Francisco who wanted to be caught dead at San Francisco General Hospital,” said Cliff Morrison, a clinical nurse specialist and former head of nursing at the hospital. That changed significantly after Morrison created the hospital’s AIDS unit in July 1983. “I couldn’t understand why all of a sudden there was this group of patients and nobody wanted to deal with them,” he said. For Morrison, it only made sense that if gay men with AIDS had nowhere else to go, they should be able—like anyone else in dire medical straits—to count on the General. Suddenly, middle-class gay men, many of them destitute because of AIDS, were literally dying to get into Ward 5A.

The ward’s patient-friendly operating philosophy was to provide the services that patients wanted. One of its unique components was a strong emphasis on mental health, considered a high priority by patients. Another was the ward’s policy to respect gay relationships. Patients chose a “significant other” who would be involved in medical decisions, and visiting hours were abolished so friends and family were welcome twenty-four hours a day. In 1990, the San Francisco Health Commission extended this policy to encourage the city’s hospitals to give visitation rights to the unmarried partners of gay AIDS patients²³³—twenty years before President Obama in 2010 ordered equal visitation rights for the same-sex partners of gay men and lesbians.²³⁴

²³³. “Visiting Rights Urged for Gay Partners,” *San Francisco Chronicle* (20 June 1990), A:20.

²³⁴. Michael D. Shear, “Obama extends hospital visitation rights to same-sex partners of gays,” *Washington Post* (16 April 2010).

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This “client-centered” approach to medical care was a radical departure from what Morrison called the “we know best, you come to us and we don’t go out to you” model that prevailed at the time. As many health care providers and AIDS researchers were to learn in the coming years, gay men were not ordinary patients. Said Morrison, “For the first time, health care found itself in the position where there were highly motivated, informed patients who said, ‘We need your assistance, but we’re not going to roll over and do everything you say to do.’”²³⁵

Ward 5A became famous for the compassionate, holistic care it provided to AIDS patients, and was emulated by dozens of specialized AIDS units in hospitals across the country. It hosted many visitors, including former Surgeon General C. Everett Koop and world-renowned bereavement expert Elisabeth Kübler-Ross. The staff were surprised and pleased by the media attention they received because it meant others would learn about the model of services they had created at the General. Said Morrison, “The only spotlight we thought we were going to get was negative, so when we had all this positive attention, I was very surprised.”

All the nurses who staffed the ward were volunteers; half of them were openly gay. A number of them eventually died of AIDS themselves. In addition to the nurses, the ward had a psychiatrist, a medical social worker, consulting psychiatrists and psychologists, and five full-time counselors from the Shanti Project.

Oddly enough, Morrison noted, initial support for the ward “did not come from gay men, particularly within the health care establishment itself.” At a time when public debates over gay

²³⁵. Cliff Morrison, telephone interview with author, 15 August 1995.

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bathhouses were heating up, there was hesitation about drawing attention to gay men's sexuality by singling out AIDS patients for special treatment. Doing so, some feared, would add to the stigma of those with the disease. While many gay men were reluctant to support the AIDS ward, straight women and lesbians didn't hesitate one moment. As Morrison put it, "Our sisters really stepped to the forefront and said to hell with everybody else, we'll do what we have to do."²³⁶

For many lesbians who got involved, politics—and sometimes the opinion of other lesbians—had little to do with their involvement. During her years at GMHC, in the early eighties, New York therapist Sandi Feinblum ran up against the misogyny of many gay men. She described the frustration of dealing simultaneously with the bigoted and fearful attitudes of the public toward AIDS, and the "women-less existence" preferred by some gay men.

"Here you have this pressure cooker and all these terrible things happening," said Feinblum. "In those days it was not unusual for us to go to someone's apartment and scrape shit off the floor, call an ambulance, then fight with the ambulance to take the person. And then you had a lot of gay men who never dealt with women, who constructed their lives not to deal with women. I met lots and lots of men who had no women friends, and except for on the job, they really eliminated women out of their lives." Despite the lack of women in their lives, Feinblum said these gay men still felt it their due as men that women should help them in their moment of need. "As in the rest of the world," she said, "women helped men, and men expected them to help."

²³⁶. Morrison interview.

VICTORY DEFERRED

As GMHC's first deputy director, Feinblum recalled, "People used to say to me all the time, 'Why do you work with AIDS and GMHC? They wouldn't work for breast cancer.'" Underscoring the nonpolitical motives that spurred her own AIDS work, she said, "That's partly true—but what did it have to do with the fact that all my friends were dying?"²³⁷

For many heterosexual women who joined the fight against AIDS, the only thing that mattered was that people—regardless of their sexual orientation—were suffering injustice. A self-described maverick social services administrator with the Dade County government, Catherine Lynch had worked for years with hurt people on issues ranging from domestic violence to rape counseling to bereavement. Her bilingual ability gave her an added glimpse into those issues within Miami's large Hispanic community. One incident among all she had seen in her career pushed her to the point she knew she wanted to focus on AIDS.

Lynch was trying to track a young Hispanic man who had been approved for placement at Jackson Memorial Hospital, Miami's primary public hospital, but then just disappeared. After finding his number in the computer, Lynch called the man's house. She spoke in Spanish with his mother, who started crying. Lynch recalled, "She started talking about how her son was dying of AIDS, and excuse her for crying but there was no one she could talk to about it. Whenever she tried to talk to her husband, he didn't want to hear about it." After a long and difficult conversation, Lynch said, "I hung up the phone and I thought, 'There is something so wrong in the world where I found this woman because I was an administrator who was bothered by a dangling loose end.' If I had not been trained as

²³⁷. Sandi Feinblum, interview with author, New York City, 26 April 1995.

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a crisis counselor, if I was not bilingual, there would be no one to help this woman.”

When Lynch took over as director of Miami’s Health Crisis Network (known since its 1998 merger with Community Research Initiative as Care Resource, Inc.), in 1988, she had no reservations about working with an organization in the gay community. “It wasn’t a risk for me to go to a gay-identified organization, possibly because I was married,” Lynch said. “I trust my gut. My gut said these are good folks, decent, honorable, caring folks.”

During the interview process, Lynch was asked what she would do if someone snubbed her at a social event because of her affiliation with an AIDS organization. She said, “If you are a relatively assertive, intelligent woman in this world, a good number of people hate you because you don’t do what you’re expected to do. The people who would stigmatize me for working in a gay organization are the people who would have stigmatized me for being me anyway.”

How did Lynch find AIDS work in comparison with the other troubling issues she’d worked on in the past? “I did not have any understanding of some of the things I was getting into,” she said. “You don’t until you experience loss after loss after loss of wonderful people. I had not understood that I was going to face this once a week, and once every month or two with someone I knew well enough to care about, to feel that it wasn’t just a loss for me but it was a tremendous loss for the community.”²³⁸

The awareness of their loss motivated many to get involved by showing they cared through direct action of one sort or an-

²³⁸. Catherine G. Lynch, interview with author, Miami, 19 May 1995.

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other. Most amazingly, people with HIV themselves refused to accept the role of victim, and frequently volunteered to help others in the same situation.

Shanti Project founder Charles Garfield borrows Swiss psychiatrist Carl Jung's concept of the "wounded healer" to describe the phenomenon of caregivers who are themselves living with, at risk for, or bereaved by AIDS. Garfield writes, "The wounded healer recognizes himself or herself in the patient, and the patient recognizes his or her reflection in the healer." Particularly when both the care provider and recipient are living with HIV, the "wounded" one and the healer are interchangeable roles. "Both caregiver and patient step through the looking glass, in a manner of speaking, and into the territory of the other," Garfield says. "Ancient healers, shamans, believed that this ability to 'move between the worlds' of health and sickness was the source of their powers to heal."²³⁹

Robert Washington was thirty-six years old in 1984. Although the HIV antibody test was not available at the time, the Washington, DC psychologist said he "knew" he was positive even though his doctor dismissed his symptoms as hypochondriacal, induced by being around people with AIDS. Subsequent testing revealed the fact Washington was infected with HIV.

Comfortable in his various identities—Black man, mental health care provider, father—it took Washington some time to become comfortable revealing other aspects of himself: gay, HIV-positive. But when Washington, then living in Chicago, got involved with the Cook County buddy program in October 1984,

²³⁹. Charles Garfield, *Sometimes My Heart Goes Numb: Loving and Caregiving in a Time of AIDS* (San Francisco: Jossey-Bass, 1995), 8.

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the experience changed his life by forcing him to learn to be comfortable with far graver matters than others' perceptions of his sexuality.

"My first buddy was a hustler," Washington told me, "a young African-American man who was twenty, uneducated, and absolutely gorgeous." The clinic staff assigned him to Washington because they felt he had the professional expertise to handle the case. "This young man was quite distraught, angry, upset—all the things you might expect," said Washington. "But more than anything else, he was quite afraid he was going to be damned to hell, something I didn't believe." Long phone calls taught Washington the "power of presence," simply being there for someone. He said, "Nothing I could say would take away the feeling, but I could sit on the other end of the phone and just be there for him."

Washington's buddy lived for nine months, during which time they became almost constant companions. Washington said, "It was the first time that I was a witness, an intimate witness, to the dying of somebody. And it changed me." Although he is a psychologist, Washington had no formal training in work with death and the dying at that point, so he went from the gut. He recalled, "When it became clear he was going to die, he called me and told me. I picked him up—literally, I had to pick him up and carry him down the stairs—and took him to the Cook County Hospital, where he was put in the intensive care unit. He died peacefully. He died young—a couple months after his twenty-first birthday."²⁴⁰

Describing voluntary efforts to care for people with AIDS, Philip M. Kayal writes, "AIDS is such a shattering human event

²⁴⁰. Robert Washington, interview with author, Washington, DC, 25 March 1995.

VICTORY DEFERRED

that it is only possible to capture its horror in a direct face-to-face encounter—by living in a relationship with a PWA.” Like Robert Washington, gay and nongay people alike who have been involved in providing care are changed by the experience. For individuals who have the virus themselves, the experience can be empowering as they support and encourage others’ efforts to survive and thrive with it. It can also be a sobering glimpse of what may lie ahead.

No matter who it is and what their HIV status, volunteering and providing AIDS services are profoundly political acts. As Kayal puts it, AIDS volunteerism provides “the prime opportunity for both intimately knowing AIDS and understanding its political dimensions.”²⁴¹

Gay men, lesbians, and others involved in AIDS-related services and political work often speak of the AIDS “movement.” By this they mean the broad community of people—including both gay and nongay people, men and women, and all races—who seek a rational response to the epidemic; medical and social services that treat people with HIV with skill and compassion; a voice for clients in how and what services are provided; and, ultimately, accessible and affordable treatment for people in general who are afflicted by life-threatening illness.

People caring for their own formed the core of what became a broad community of concerned, caring people—a real army of lovers—who, despite their many social and demographic differences, shared one belief: People with HIV deserve kindness, care, and effective services merely because they are fellow human beings. AIDS service organizations were created essen-

²⁴¹. Philip M. Kayal, *Bearing Witness: Gay Men’s Health Crisis and the Politics of AIDS* (Boulder, Colo.: Westview Press, 1993), xv.

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tially to channel and coordinate the community's outpouring of caring. This multihued, multilingual, cross-generational, cross-gendered band became as formidable an army as the world has ever seen, their love in action a force to reckon with.

Suzanne Ouellette, a graduate psychology professor at City University of New York, for years studied the role of volunteers in providing AIDS services, particularly at GMHC, the organization that pioneered so many of them. Ouellette described to me a survey of five hundred GMHC volunteers, conducted in the late eighties, in which the question was asked: What should happen to GMHC if a cure for AIDS were found tomorrow?

Of course there were what Ouellette called the "pragmatists," who said the agency should celebrate and close its doors, its mission at last accomplished. But 75 percent of the volunteers said that GMHC should remain in operation. One group said the agency should shift its focus to other pressing gay community issues, such as antigay violence and lesbian health concerns. Another group went even further. Said Ouellette, "They saw GMHC as a place that could fix just about anything that was wrong with society. There would always be social problems, and the special kind of helping that went on at GMHC would have to continue."

She noted that many people have been drawn to organizations like GMHC precisely because of the specialness of their work. "GMHC represents a very important kind of community in which help and caring and sharing goes on," she said. "A lot of straight people get drawn to that, too." Ouellette added that while GMHC plays an important role in the gay community, "if

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there's any hope for us, it's establishing our identity but then being able to find some larger way that we're linked."²⁴²

AIDS caregiving forged bonds among many who, had it not been for their concern about people with AIDS, were unlikely to have met—let alone worked, struggled, and wept together. The result has been a level of solidarity that, before AIDS, gay people never had with one another, let alone with heterosexuals. Their involvement in caring for people with AIDS politically galvanized many bereaved parents, concerned coworkers, and huge numbers of gay men and lesbians. They saw firsthand the correlation between the hostility of antigay politicians and the struggle to provide compassionate care for people with AIDS.

Demagogues like the late Senator Jesse Helms and the blowhards of the fundamentalist "Christian" right continued to retch out one diatribe after another against the "deliberate, disgusting, revolting conduct" Helms said led to AIDS, typically doing so in the name of their twisted version of morality and a vengeful god.

AIDS caregivers, on the other hand, offered love. Not the mushy, sentimental kind glamorized in fairy tales and soap operas, but love based on an understanding of shared humanity, that seeks through acts of mercy to cushion the blow of mortality that eventually strikes us all down. Beginning with those who have HIV themselves, and radiating outward to include lovers, friends, family members, neighbors, and coworkers, the "troops" of caring Americans who have worked and volunteered to provide AIDS services in communities across the country have supported the dignity and prolonged the lives of those with the disease. In doing so, these "wounded healers" have

²⁴². Suzanne Ouellette, interview with author, New York City, 27 April 1995.

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discovered a richness of life that can't be bought and that not even bigots like Helms could steal.

While those caring for people with AIDS found new richness in their lives, others working to help gay men adopt safer behaviors faced an even more daunting challenge than right-wing bigotry: helping gay men to love and respect themselves and one another enough to prevent HIV from spreading in the community. Not even the “love in action” of AIDS volunteers would be sufficient to prevent many men from endangering themselves and others in risky behavior. Gay men would ultimately have to find their own way of being safe and sexual at the same time. In doing so, they would find themselves engaged in some of the fiercest battles—psychological, social, and political—ever to be waged in the war against AIDS.

PART 4

SAFETY DANCE

*One moment of passion, one lapse of concentration,
a second out of consciousness,
an instant of ecstasy and it's done.*

HARVEY FIERSTEIN, *SAFE SEX*

The devotion to sexual “freedom” of the seventies refused to die even as AIDS killed increasing numbers of gay men in the eighties. As gay America was devastated, gay men looked to the new AIDS organizations for direction, trusting them to filter information from government scientists through a gay-friendly screen. “Safe sex” became a kind of religion, and prevention educators its “priests,” arbiters of gay community values and molders of gay men’s psyches and sex drives. Decreeing safe sex to be the new community “norm,” and shaming those who strayed from it, educators believed they could stop the epidemic.

Astonishing numbers of gay men changed their behavior, and the rate of new HIV infections slowed in the community. The US Public Health Service could claim little credit for the change, mired as its own prevention efforts were in conservative Republican politics that viewed helping gay men survive as “promoting” homosexuality.

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When news surfaced that some gay men, weary of being told how to have sex and now able to know whether or not they were infected, were having unprotected sex, they were once again condemned as sexual outlaws—by other gay men. Fortunately, a few people were willing to cut through the bombast to point out that, just maybe, gay men would have safe sex when they themselves felt safe, and, just maybe, homophobic bigots and useless federal prevention programs should be the target of the community's rage—not other gay men.

TWELVE

In the spring of 1983, Edmund White was fresh from a book tour promoting his latest novel, *A Boy's Own Story*, the tale of a troubled adolescent coming to grips with his homosexuality. Perhaps it was his absorption in the character he'd created that led White, in a June 1983 essay in *Mother Jones*, to celebrate the "adolescence" of "contemporary big-city gay life." He likened this gay subculture to the ancient royal courts of Japan and Versailles, where "participants can afford to behave as they please," and the wealthy enjoyed "the rapid succession of affairs, the scheming and intrigue, the scrambling after popularity, the dismissal of the solid future in favor of the shimmering present."

For White, like many other big-city white gay men, the guilt-free slide in and out of sexual liaisons, the assumption that all gay relationships are "open," and a seemingly innate ability to distinguish sex and love were what separated gay men from heterosexuals—as well as from "mere" homosexuals "whose lives follow straight conventions," as White dismissively put it in the essay.

To the man who had surveyed the landscape of late 1970s gay life in *States of Desire* and was a cofounder of Gay Men's Health Crisis, the casual couplings that he and other affluent white gay men in New York and elsewhere drifted in and out of were just some of the trappings of a privileged life they took for granted. "Gays," wrote White, "not only consume expensive vacations, memberships in gyms and discos, cars, elegant furnishings, clothes, haircuts, theater tickets and records, they

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also consume each other.” What’s more, he asserted, “A uniform gay culture is being created: a standard look, with its emphasis on macho clothes and the heavily muscled body; and a uniform set of values, cheerfully hedonistic though recently imbued with a sense of responsibility to less fortunate members of the gay community.”²⁴³

The title of White’s essay, “Paradise Found,” seemed, even at the time it was published, to redefine the word “irony” with its “let them eat cake” attitude toward the presumably less enlightened who might value something like commitment and fidelity—even as the latter-day guillotine was dropping on so many men like White. In fact, the irony of White’s words in 1983 was palpable when a photograph of him appeared in the *New York Times Magazine* a decade later with the caption, “I’m HIV positive. I need your help.” Was it the gay culture’s cheerful hedonism or its sense of responsibility to less fortunate members to which he now appealed?

Looking to ancient history to rationalize modern promiscuity, White overlooked the best-known example of approved homosexual love: ancient Greece. But he had to ignore the Greeks because, as Gabriel Rotello notes in *Sexual Ecology*, “The Greeks may have accepted homosexuality, but they hardly condoned promiscuity. Immoderation and lack of restraint were among their chief horrors.”²⁴⁴

Not all gay men in 1983 agreed with White that being gay implied being promiscuous. Many were in coupled relation-

²⁴³. Edmund White, “Paradise Found,” *Mother Jones*, June 1983, 10–16.

²⁴⁴. Gabriel Rotello, *Sexual Ecology: AIDS and the Destiny of Gay Men* (New York: Dutton, 1997), 224–25.

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ships, and many of those relationships were monogamous as well. Others questioned the status quo of the urban gay ghetto, where promiscuity was an expected fact of gay life—and where casual sex with multiple partners was referred to as anything else but promiscuity because the word itself was viewed as tacky and “politically incorrect” among men such as White. Still others had already awakened to the fact that there was a fatal sexually transmitted disease epidemic underway, and that it had serious sexual and political ramifications.

In Boston the same month that White’s essay was published, gay psychiatrist Marshall Forstein was one of a panel of speakers addressing several hundred gay people who had gathered at historic Faneuil Hall on June 16 for the city’s first-ever forum on AIDS. Thirty Bostonians had been diagnosed with AIDS to that point; half were dead. Forstein recalled telling the audience that although sex should remain an important part of the lives of gay people, “we needed to use condoms, which we knew would protect us from viruses because it works with hepatitis and other STDs, and we also needed to make every effort not to curtail having sex, but change how we had sex.”

Then Forstein hit the group directly in the status quo. “For years we were giving each other diseases and saying it’s no big deal,” he told them. “But in fact people have died from these diseases. People with gonorrhea have lost use of their joints. People with syphilis have gone crazy. People with hepatitis have died at a rate of about ten percent of those who get it.”

Underlying Forstein’s remarks was a fundamental question about the degree to which gay men’s “internalized homophobia” affected their sexual relationships with other men. Was it love they were making, or an unconscious desire to harm? He wondered, “How much of our anger towards our position in the world was being acted out through our anger towards each

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other as men—so when we fucked somebody, we were experiencing rage as well as lust?” He said he wasn’t saying gay people shouldn’t be sexual and play by their own rules, “but that we needed to think about how we were going to handle the next few years—or some of us might live to see the devastation in our community that we would have brought on ourselves.”²⁴⁵

While many gay men, like Edmund White, had transplanted themselves to the relative openness of the big cities to escape small towns and small minds, they often struggled between their own desire for love and acceptance by a special partner and the availability of guilt-free sex with any number of randy partners to be had virtually any time and any place.

In *Fabulous Ride Into the Unknown*, his one-man play (formerly known as *Decade*) about the effects of the AIDS epidemic on ten different men, Bruce Ward movingly captures the ambivalence that so many men felt in the urban gay world at the dawning of the epidemic—torn between its free love and the enslaving loneliness that drove many of them to test their mortal limits in unchecked drug use and sexual abandon.

Ward’s first character, Melvin, echoes White’s own words, though he is more forthright about the ambivalence of an existence of one-night stands strung end to end. With Donna Summer’s disco hit “I Feel Love” throbbing behind him to set the scene, Melvin says, “Sometimes that’s all I want, just to lie there with a warm body next to mine.”

Equivocating about the man actually lying in bed next to him, Melvin continues, “We’ll get dressed and maybe exchange numbers...but maybe not...and we’ll say goodbye and maybe

²⁴⁵. Marshall Forstein, MD, interview with author, Washington, DC, 13 September 1995.

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see each other again. But maybe not. And it'll be worth it. It'll all be worth it. 'Cause I am young and free and gay, and life is a fabulous ride into the unknown and I know I'll 'never pass this way again!' And maybe someday, someday soon, I'll want that body next to me to be the same one every night, to be there to come home to and to grow old together. But not now... 'Cuz there's time. Lots of time."²⁴⁶

But by mid-1983, the clock was already ticking on the community's, and the nation's, ability to stem the spreading epidemic. Many gay men were themselves like time bombs set to go off at some unknowable point in an explosion of horrific infections related to the mysterious new disease.

The same month that White's essay appeared, and that Boston held its first AIDS forum, gay health and political activists gathered in Denver for the Fifth National Lesbian and Gay Health Conference, with a second national forum on AIDS. Ginny Apuzzo and Pat Norman led a workshop that looked at blood banking, future relationships between public and private agencies, and the implications of AIDS being labeled a disease of the gay community and other disenfranchised groups. Other sessions in the AIDS forum considered such topics as the epidemiology of AIDS; the emotional impact on patients, care providers, and society at large; and a report on what would become known as the San Francisco "model" of coordinated AIDS services. Tim Westmoreland, chief counsel to the House Subcommittee on Health and the Environment, and gay health-care activist Lawrence "Bopper" Deyton were given "Health Pioneering in the Eighties" awards "for their lobbying and political research efforts in facilitating AIDS appropriations."

²⁴⁶. Bruce Ward, *Fabulous Ride into the Unknown* (formerly titled *Decade: Life in the 80s*), unpublished play, 1992.

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Now that basic support services were in place through the newly formed AIDS organizations, gay people's attention turned increasingly to developing more systematic prevention efforts to replace the earlier ad hoc delivery of information (and conjecture) as it dribbled down from doctors and scientists. To that end, another workshop at the forum featured gay medical and mental health professionals from San Francisco, looking at "Creating Positive Changes in Sexual Mores." The conference program promised a session in which "Positive aspects of the gay male sexual revolution will be examined with implications of healthy sexual behavior in the context of the current AIDS/sexually transmitted disease crisis." Overall, the program's objective was "to initiate positive change towards attainable, safe and satisfying sexual behaviors for gay men."²⁴⁷ Psychologist Steve Morin was one of the panelists for the "sexual mores" workshop in Denver.

Morin recalled in an interview how he and other gay health professionals in San Francisco developed the city's—and the nation's—first real "safe sex" guidelines for gay men. In 1982, Morin joined fellow psychologist Leon McKusick, who later died from AIDS, in gathering data through questionnaires given to people coming out of bars, initially in the Castro and then some other sites. People responded to ads in newspapers, bathhouses, dance clubs, and by being "nominated" through networks of couples. The goal was to determine how people were changing or reacting to news as it became available.

²⁴⁷. Conference program, The Fifth National Lesbian/Gay Health Conference, Denver, Colorado, 9–12 June 1983. Sponsored by the National Gay Health Education Foundation, American Association of Physicians for Human Rights, and the Gay and Lesbian Health Alliance of Denver.

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Around the same time, the K.S. Foundation began to formulate its official “message.” Morin, who participated in discussions at the foundation and the city’s public health department, said, “We had a somewhat different view, I think, in San Francisco than in a lot of other places in the country, at least among the gay community leadership. We were more willing to put out there to people that this was probably an infectious disease and that you could get it with one sexual contact.”²⁴⁸ Morin helped to develop safe sex materials for distribution by the Bay Area Physicians for Human Rights (BAPHR) and the K.S. Foundation.

Operating on the assumption that whatever caused AIDS was likely to be spread in the same ways as hepatitis B, Morin and BAPHR officials Rob Bolan and Tom Smith categorized sexual activities into safe, possibly safe, and unsafe practices. As defined by BAPHR, “safe sex” includes mutual masturbation, social kissing, body massage and hugging, body-to-body rubbing, “light S&M activities,” and using one’s own sex toys. “Possibly safe” practices include anal intercourse with a condom, “fellatio interruptus,” mouth-to-mouth kissing, urine contact, vaginal intercourse with a condom, and oral-vaginal contact. “Unsafe sex” practices include receptive and insertive anal intercourse without a condom, “manual-anal” intercourse, fellatio, oral-anal contact, and vaginal intercourse without a condom.²⁴⁹

²⁴⁸. Stephen Morin, interview with author, Washington, DC, 20 March 1995.

²⁴⁹. Jackson Peyton, “AIDS Prevention for Gay Men: A Selected History and Analysis of the San Francisco Experience, 1982–1987” (San Francisco: San Francisco AIDS Foundation, 1989).

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In New York, GMHC persisted in telling gay men simply to limit their number of sexual partners and make sure their partners were “healthy”—a message the KS Foundation also had issued in 1982, before the BAPHR guidelines. GMHC didn’t want to offend gay men by presuming to tell them anything about specific sexual practices. While San Franciscans had moved on to the soon-to-be-proven assumption that the cause of AIDS was probably an infectious agent, New Yorkers took the attitude that, unless they could present irrefutable evidence, they couldn’t expect gay men to listen.

Rodger McFarlane, who became GMHC’s executive director in the same month as the Denver conference was held, told me, “We were all taking the same fucking drugs, sitting in the same bathhouses, sprayed by the same mosquito sprays in the same resorts. How dare you suggest we knew it was infectious.” Without that certain knowledge, McFarlane argued that GMHC couldn’t have done prevention programs any earlier. But his memory blurred and his argument faltered when he downplayed GMHC’s leading role in the community. “I defy you to suggest that GMHC was as influential or responsible as the CDC,” he said.²⁵⁰

McFarlane failed to mention that gay men *did* look to GMHC, and to the gay press, for information about AIDS. In fact, one of the main reasons for GMHC’s formation—as it was for the San Francisco AIDS Foundation and the other earliest AIDS organizations formed by gay people—was to disseminate information to the gay community. As Larry Kramer put it, “[GMHC] was not founded to help those who are ill. It was founded to protect the living, to help the living go on living, to

²⁵⁰. Rodger McFarlane, interview with author, New York City, 4 March 1995.

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help those who are still healthy to stay healthy, to help gay men stay alive.”²⁵¹

Gay men counted on these organizations to provide the “truth” about AIDS. The CDC, like the rest of the government and medical establishment, was seen as just another oppressor. In fact, in the earliest years of the epidemic, gay and AIDS groups throughout the country—and in other countries—looked particularly to GMHC and the San Francisco AIDS Foundation for guidance on how to approach the AIDS crisis. The AIDS educational materials developed by the two groups were widely circulated and highly influential in gay communities across the nation and, literally, around the world.

Like the disagreement between the New Yorkers and San Franciscans over what, exactly, was safe sex, the gay community’s earliest efforts to translate scientific information about AIDS into educational messages for gay men were pulled in two directions. Some believed that whatever was said had to be couched in “sex-positive” language, while others believed that the only way that gay men would change their behavior was if they were scared enough to do so.

Although they were accused of being “sex-negative” because of their May 1983 pamphlet *How to Have Sex in an Epidemic: One Approach*, Richard Berkowitz and Michael Callen made it clear that such accusations were groundless as the two men were quite frank about their own busy sex lives. They were also clear—and would soon be vindicated—that whatever was causing AIDS was likely transmitted most efficiently through receptive anal intercourse. They wrote, “Because of the ridiculous

²⁵¹. Larry Kramer, “An Open Letter to Richard Dunne/1987.” In *Reports from the holocaust* (New York: St. Martin’s Press, 1989), 103.

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and dangerous stereotype that being ‘passive’ and getting fucked are somehow ‘unmanly,’ some gay men tend to be defensive about any warnings concerning the medical hazards of anal passivity.” They added, “Remember that the issue is disease—not sex.”²⁵²

In late 1983, the San Francisco AIDS Foundation produced a poster depicting two naked men embracing, with the caption “You Can Have Fun and Be Safe Too.” Respectful of gay men who had heard all their lives they were “sick” for loving other men, the poster was explicit and positive, yet subtle, in its message—and caused an uproar among nongay San Franciscans.²⁵³

Another group in San Francisco believed a fear-based campaign was needed to discourage gay men from having sex at all. Their materials depicted an hourglass with blood-colored sand pouring into the bottom, with the slogan “Time Is Running Out.” One of the earliest AIDS posters in San Francisco was nothing more than a blown-up color photograph of the Kaposi’s sarcoma lesions on the foot of early AIDS patient Bobbi Campbell. It was simple and bone-chilling in its directness and horror.

Ultimately, the AIDS Foundation took a middle course, adopting the slogan “The Best Defense Against AIDS Is Information.”²⁵⁴ Give men enough information, it reasoned, and they

²⁵². Richard Berkowitz, *Stayin’ Alive: The Invention of Safe Sex* (New York, originally published 2003; first paperback edition 2008), 204.

²⁵³. Dennis Altman, *AIDS in the Mind of America* (New York: Anchor Press/Doubleday, 1986), 164.

²⁵⁴. Peyton, “AIDS Prevention for Gay Men.”

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would make not merely well informed, but life-saving decisions. Still, the public health and marketing professionals working with the foundation to design its first prevention campaigns faced a daunting challenge in a community whose members largely thought the best defense against AIDS was the denial of its reality.

A November 1983 survey of 650 gay men in San Francisco found that even men who were well informed about the relative risks of various sexual activities “displayed discrepancies between what they believed about AIDS and their sexual behavior.” The survey found an increase in the rate of unprotected receptive anal intercourse, despite its being considered, even at the time, to have the highest risk. Sixty-nine percent of the men surveyed who had three or more sexual partners in the previous month agreed with the statement, “It is hard to change my sexual behavior because being gay means doing what I want sexually.” On the other hand, 43 percent of those reporting two or fewer partners agreed with the statement, “I can recall seeing a victim in the advanced stages of AIDS.”

Clearly, firsthand experience with AIDS was highly effective in making men change their sexual habits to protect themselves. Leon McCusick and his fellow behavioral researchers concluded that other motivational strategies would be needed beyond merely providing information. “Sexual behavior,” they wrote, “may be comparable to other high-risk behaviors such as tobacco smoking, obesity, non-seat belt use, and alcohol consumption, where knowledge alone is not sufficient to change behavior.”²⁵⁵

²⁵⁵. Leon McKusick, William Horstman, Thomas, J. Coates, “AIDS and Sexual Behavior Reported by Gay Men in San Francisco,” *American Journal of Public Health* 75 (May 1985), 493–96.

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Not long after the discovery of the AIDS virus was announced in the spring of 1984, the AIDS Foundation developed the first plan anywhere for a systematic strategy to assess and, it hoped, alter the high-risk sexual behavior of gay men on a large scale in San Francisco.

The Comprehensive AIDS Education and Prevention Plan, written by consultant Sam Puckett, aimed to raise awareness of the close relationship between alcohol, drug abuse, and unsafe sex; the decrease in unsafe sex practices; and the continuing drop in the city's rate of rectal gonorrhea—considered a proxy for AIDS risk. The plan committed the AIDS Foundation to being sex-positive, promising to operate “on the conviction (despite some evidence from the past to the contrary) that gay and bisexual men fundamentally want to be healthy and productive, want to live, and want to deal responsibly with the AIDS issue as rational, intelligent adults.”

The cornerstone of the plan, which was funded by the San Francisco Department of Public Health, was a citywide random sample telephone survey of five hundred gay and bisexual men. Besides providing the city's first-ever demographic profile of gay male residents, the thirty-minute telephone interviews were intended to assess the men's risk behaviors and the attitudes that influenced those behaviors. A follow-up survey would measure behavior change. In addition, the AIDS Foundation conducted four small focus groups that sampled the attitudes about AIDS and sexual activities of forty randomly chosen gay men.

Largely because of these early focus groups in San Francisco, the involvement of community members in the design of prevention campaigns would become a central tenet of prevention efforts nationwide.

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Focus group participants reported reductions in the number of their sex partners along with attempts to select partners who were perceived as healthy and not promiscuous—just as they’d been advised to do by the AIDS Foundation. They said they relied on the gay press and other community sources for information about the AIDS crisis. Although the men had considerable awareness of what was thought to be safe and unsafe, most of them were willing to eliminate the unsafe practices that didn’t interest them—but were not willing to give up their own favorite sexual activity, even if it was considered unsafe.

Besides a high level of concern about the political implications of the AIDS crisis for the gay community, the men also felt that AIDS could have the unexpected positive effect of improving the quality of gay relationships by fostering more monogamy, intimacy, and closeness in sexual relationships.²⁵⁶

Armed with an unprecedented knowledge of gay men and their sexual behavior, the AIDS Foundation used a multifaceted “hybrid” strategy to saturate the city of San Francisco with information about AIDS and how to avoid it. Jackson Peyton, the foundation’s director of education from 1984 to 1987, called this period the “golden age of prevention.”²⁵⁷ Innovative programs were created, and Peyton was given a fairly large budget with which to provide AIDS education to gay men. The AIDS hotline offered callers information and referrals. A People with AIDS Switchboard provided recently diagnosed individuals with a

²⁵⁶. San Francisco AIDS Foundation, *A Comprehensive AIDS Education/Prevention Plan for Fiscal Year 1984–85*, 18 June 1984.

²⁵⁷. Jackson Peyton, interview with author, Washington, DC, 20 February 1995.

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place to talk with others in the same situation. Ads in the initially resistant gay press told gay men, "Let's stop making excuses. Let's stop the spread of AIDS." Brochures were designed to reach various subsections of the community. Condoms were distributed. Educational events, from small gatherings of a few men to large public forums, were routinely held. And the AIDS Foundation and other AIDS-related organizations established a presence at the city's street fairs and the annual Lesbian and Gay Freedom Day Parade.

While the AIDS Foundation's focus groups originally were intended simply to provide a marketing research base for the agency's education program, the men who participated in them got a great deal out of them as well. For many of them, this was the first time they'd had a chance to talk with other gay men about the growing epidemic, to feel they weren't alone in facing its horrors or in their struggles to change their sexual behavior.

The Stop AIDS Project emerged in 1984 from the original AIDS Foundation focus groups and the interest of gay men in having additional programs. Stop AIDS recruited gay men throughout the city to participate in one-time, four-hour meetings in which they discussed everything from what AIDS meant for them personally, to the challenges of safe sex, to what kind of gay community they envisioned in the future and how they could help make it a reality. Finally, the men were asked to pledge themselves—and to support one another—to practicing safe sex as their contribution toward stopping the AIDS epidemic.

Researchers in 1984 in other cities also began to gather information about gay men and their sexual habits that had never before been available. In New York, for example, psychologist John Martin and his research partner Laura Dean, began studying the impact of AIDS on gay men's sexual behavior.

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Actor and playwright Bruce Ward was living in New York at the time and worked with Martin and Dean as they interviewed 745 gay men. Ward recalled, “The first summer was really draining because people were freaking out. I was taking that in as an interviewer, and it was really affecting me.”²⁵⁸ The interviews revealed that kissing had declined by 48 percent, oral sex by more than 60 percent. Anal intercourse of any kind had declined by more than 75 percent. They also found that the men seemed to be having more sex, but with fewer partners—and more often at home than in places like bathhouses or back-room bars.²⁵⁹

As with the focus groups in San Francisco, one of the unexpected effects of recruiting gay men for research studies was that the men who participated in them discovered a heightened political awareness of what it meant to be gay in America at a time when their own government seemed to be doing all it could to ignore the growing epidemic. Beginning in 1984, the Multicenter AIDS Cohort Study (MACS) recruited gay men in Baltimore, Chicago, Los Angeles, and Pittsburgh to participate in the largest (4,950 men) longitudinal study of gay men in the AIDS epidemic. MACS is an ongoing biomedical study of the natural history of HIV (and its medical management) in gay and bisexual men, funded by the National Institute of Allergy and Infectious Diseases. Men were recruited through gay publications, clinics, college campuses, gay organizations, and in bars.

²⁵⁸. Bruce Ward, interview with author, Boston, 24 July 1995.

²⁵⁹. John L. Martin, “The Impact of AIDS on Gay Male Sexual Behavior Patterns in New York City,” *American Journal of Public Health* 77 (May 1987), 578–81.

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When Curt Decker was asked by a doctor from Johns Hopkins University to help recruit twelve hundred gay men for the MACS in Baltimore, Decker, a well-known member of the Baltimore community, recalled saying, “I don’t even know if there are twelve hundred gay men in Baltimore! But no way are we going to get twelve hundred men in this blue collar, closeted city to come forward and pour out all their most intimate details about sex, drugs, and alcohol use.”

Decker described his efforts to recruit gay men for the MACS at the Hippo, a popular dance bar, asking them to stop the music so he could talk to the crowd. “We were practically stoned,” he said. “People said, ‘Don’t bring us down, we’re out here having a good time, don’t talk about AIDS.’” The next step was to offer door prizes if the participants would commit to making all the required visits to the clinic each year for the expected four years of the study.

As it turned out, the prizes and other enticements weren’t needed, and the study continues to this day. Decker, who is a lobbyist in Washington on behalf of people with disabilities, said, “What I discovered is that as we got people to show up, it was a very politicizing kind of experience. One thing I liked about the MACS study so much—apart from my involvement in research—is that I thought it was a very political statement.”²⁶⁰

At first, men would go into the clinic for their MACS visit and give blood, feces, urine, semen—and toenails, because the epidemiologist felt that a lot of the body’s minerals end up in the toenails, making them a good source of “information” about someone’s health. When an antibody test finally became available, in March 1985, there was no further need for toenails or

²⁶⁰. Curtis Decker, interview with author, Washington, DC, 13 February 1995.

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bodily fluids other than blood. In fact, the MACS by that point already had three blood samples from each man in the study. Now it was possible to know who was and was not infected, and who had seroconverted since the beginning of the study. Thirty-one percent of the participants in Baltimore were already HIV-positive. Altogether in the four MACS cities, 1,809 men of the original 4,954—nearly one in three—were HIV-positive at “baseline.”²⁶¹

The Enzyme-Linked Immunosorbent Assay (ELISA), the first antibody test, initially was intended to screen the blood supply, rather than to be used as a diagnostic test for individuals. While it provided information about whether or not someone had been exposed to the virus, no one knew what, exactly, exposure to the virus and the presence of antibodies meant.

Moreover, no one knew how the information provided by the test might be used. Fearing yet further—and even more consequential—“bad blood” stigma, gay rights and AIDS groups warned gay men not to be tested. No one knew at the time whether a positive test meant that one would actually develop AIDS, or that he was already immune. There were no real treatments even if a positive test did prove to mean an ongoing infection. And there was the very real chance that an already hysterical public would insist that draconian measures be taken against those with antibodies in their blood.

At the first international AIDS conference, in Atlanta in April 1985, a small but vocal minority of researchers advocated mass testing of at-risk individuals as an educational technique.

²⁶¹. R. A. Kaslow, D. G. Ostrow, R. Detels, J. P. Phair, B. F. Polk, C. R. Rinaldo Jr., “The Multicenter AIDS Cohort Study: rationale, organization, and selected characteristics of the participants, *American Journal of Epidemiology* (1987), 310–18.

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Former CDC official Don Francis told me he personally thought it was inevitable that mass testing would become part of the total AIDS prevention picture. Breaking ranks with other gay leaders, former National Gay Task Force codirector Bruce Voeller also advocated mass testing as part of the educational program for gay men at risk for AIDS. From his own experience, he claimed that gay men would change their sexual behavior if confronted with a positive test.²⁶² "Take the Test!," he urged gay men in the *Advocate*.²⁶³

Despite the warnings of gay leaders, many people did take the test. The *Washington Post* noted that at Whitman-Walker Clinic in the late summer of 1985, "since recent publicity about AIDS, including the news that actor Rock Hudson has the disease, the clinic's Wednesday night screening sessions have been filled to their fifty-person capacity."

But in San Francisco, where homosexuals had long understood the inextricable link between the personal and political aspects of their lives, gay men by and large avoided the test. Although they had expressed interest in a hypothetical test, Steve Morin said at the time, "As the test became a reality, the psychological conflicts became more real."²⁶⁴ That no one knew the real meaning or significance of the test, and that the AIDS Foundation warned not to take it, were reasons enough for many gay men in the gayest city in the country to ignore it—

²⁶². Cindy Patton, *Sex and Germs* (Boston: South End Press, 1985), 44.

²⁶³. Bruce Voeller, "Take the Test!" *The Advocate* (30 April 1985).

²⁶⁴. Paul Berg, "To Know You've Been Exposed," *Washington Post* (4 September 1985), Health section, 11.

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thus delaying the day of reckoning for the nearly half of all gay men in San Francisco alone who would eventually learn they were infected with HIV.²⁶⁵

As the gay community sounded alarms over the potential uses and abuses of the antibody test, the Defense Department on October 24, 1985, ordered the beginning of what would be the largest AIDS screening program in the world. All recruits were to be tested, and positives would be refused entry to the armed services. Those already in the military who tested positive on the mandatory periodic tests would be discharged.²⁶⁶ A military long obsessed with ousting homosexuals from its ranks seemed, to some anyway, to have found the kind of marker for homosexuality that had never been found among the gay men who had served in the U.S. military since there was a military to serve in—these men were mostly undetected because they were, for all intents and purposes, indistinguishable from everyone else.

It wouldn't be until 1989, four years after the test became available, that GMHC finally advocated HIV testing and many more gay men learned their antibody status. But by 1987, researchers were reporting vast reductions in the number of new HIV infections among gay men in the hardest-hit cities. In New

²⁶⁵. Warren Winkelstein, Jr., et al., "The San Francisco Men's Health Study: III. Reduction in HIV transmission among homosexual/bisexual men," *American Journal of Public Health* 76 (June 1987), 685–89.

²⁶⁶. Randy Shilts, *Conduct Unbecoming: Gays & Lesbians in the US Military* (New York: St. Martin's Press, 1993), 504.

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York, the rate of rectal gonorrhea dropped by 80 percent between 1983 and 1986.²⁶⁷

In San Francisco, the rate of HIV infection among gay men remained stable at about 50 percent. But new infections had decreased from an estimated 18.4 percent per year between 1982 and 1984, to only 4.2 percent by the first six months of 1986. The number of reported cases of rectal gonorrhea in the city had plunged from nearly 300 in 1982 to less than fifty.²⁶⁸ The CDC noted that these declines coincided “with the period of heightened awareness and concern about the incidence of acquired immune deficiency syndrome among homosexual males.”²⁶⁹

It was described as the greatest behavior change ever seen in public health. “Education has been a dazzling success with homosexuals,” proclaimed *US News & World Report*.²⁷⁰ It seemed the gay community had managed to get AIDS under control, gay men had modified their high-risk behavior to avoid transmission of the virus, and the community could get back to the business of gay liberation.

²⁶⁷. National Research Council, *The Social Impact of AIDS in the United States* (Washington, DC: National Academy Press, 1993), 263.

²⁶⁸. Winkelstein et al., San Francisco Men’s Health Study.

²⁶⁹. “Declining Rates of Rectal and Pharyngeal Gonorrhea Among Males—New York City,” *Morbidity and Mortality Weekly Report* 33 (1 June 1984): 295–97.

²⁷⁰. Kathleen McAuliffe et al., “AIDS: At the Dawn of Fear,” *US News & World Report* (12 January 1987), 60–70.

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Riding this wave of optimism, San Francisco's Stop AIDS Project closed its doors in 1987. It seemed gay men "got it," that they knew what they needed to do and not do in order to protect themselves and one another. Not only were the STD rates down and gay men reporting less risk behavior overall, but they seemed in general to be having less sex. Prevention educators congratulated themselves for stemming the tide of infection and reshaping gay community sexual norms.

But safe sex wasn't the only reason for the drop in HIV and other sexually transmitted infections. Some men became celibate because of a consuming fear of AIDS bordering on pathology. "Jack," for example, described in a *Newsweek* article in early 1986 as "a twenty-nine-year-old gay artist in Chicago," told the magazine that he had practically become a recluse. An experience with another man, who had AIDS but didn't tell him, left him frightened and cynical. "I told him it was the end of my innocence because from now on I'm not going to trust anybody," said Jack. Now he stayed home, night after night. "Basically," he said, "I make love to my VCR a lot."²⁷¹

Despite the reports from hard-hit cities, it is safe to say that most gay men at this point were indeed still having sex, a good deal of it unsafe. If big-city homosexuals had changed their behavior, it could be attributed to their having access to the messages put out by AIDS organizations and a strong chance of personally knowing someone who had the disease. This was not the case for their brothers in smaller towns and rural areas.

The first of many so-called "second waves" of the AIDS epidemic was already rolling in to shore as gay men outside the major coastal cities ignored the epidemic and partied on. In

²⁷¹. Barbara Kantrowitz, "Fear of Sex," *Newsweek* (24 November 1986), 40, 42.

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New Mexico, for example, a 1987 study reported that 20 percent of a group of 166 gay men were already HIV-positive. Seventy percent of them reported practicing receptive anal intercourse in the past twelve months, and only 13 percent used condoms. A history of having had sexual partners outside of New Mexico was correlated to an increased risk for seropositivity.²⁷²

The intermingling of gay men in the major cities—men from small towns frequently visit or move to cities like New York or San Francisco—meant it was inevitable that HIV would spread from the coastal cities, where it first appeared, to the heartlands. In the major coastal cities themselves constant influxes of gay men—many of them becoming sexually active for the first time—meant that community efforts to create social norms that supported safe sex were undermined by the very mobility that brought so many gay men to the cities in the first place.

Daniel Wohlfeiler, a former Stop AIDS Project education director, said, “In 1987, the day the Project shut, there was a community norm that favored safe sex. But that norm is only as durable as the community is static.” As he pointed out, San Francisco is anything but static: In 1987, upwards of a third of the gay men in the city had lived there less than two years. Said Wohlfeiler, “The norm is obviously not going to withstand that kind of transience.”²⁷³

²⁷². Clifton C. Jones et al., “Persistence of High-Risk Sexual Activity Among Homosexual Men in an Area of Low Incidence of the Acquired Immunodeficiency Syndrome.” *Sexually Transmitted Diseases* (April–June 1987): 79–82.

²⁷³. Daniel Wohlfeiler, telephone interview with author, 15 February 1995.

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Clearly it was going to take more than brochures, posters, and workshops to make gay men alter their entrenched sexual habits. As Leon McCusick had pointed out in 1983, knowledge alone isn't enough to make people change behavior they enjoy, even if they know its potential risks. By the time Stop AIDS closed, Jackson Peyton was gone from his three-year stint as education director for the AIDS Foundation. What he called the "golden age" of prevention ended with the realization that safe sex had not become quite as "normal" as educators believed—and that the epidemic was not going to end in the foreseeable future. Said Peyton, "I truly don't believe that anybody thought this was going to be a 'rest of our lives' kind of thing until about 1990."

That's the year the Stop AIDS Project reopened, this time with no set closing date.

THIRTEEN

In 1984, CDC teams surveyed the AIDS prevention efforts in nine different cities: Atlanta, Chicago, Houston, Los Angeles, Miami, Newark, NJ, New York, San Francisco, and Washington, DC. They found that San Francisco alone had the kind of collaboration between the public health department and community-based AIDS groups that was deemed essential if prevention education was to succeed. The teams concluded that the “translation” of scientific information into usable, understandable prevention messages required “graphic language to provide explicit advice about sexual behaviors or needle sharing.” They added that to be successful in reaching a particular population, prevention efforts “must be appropriate for and responsive to the lifestyle, language, and environment of the members of that population.”²⁷⁴

Despite the recommendations, a 1985 report by the congressional Office of Technology Assessment faulted the federal government’s inadequate attention to AIDS prevention education. The OTA noted that it had been mostly left to those at greatest risk—gay men and injection drug users—to educate themselves. This made a certain amount of sense, until one realized that those groups, particularly drug users, had neither the financial nor scientific resources on their own to conduct the kind of massive national prevention campaigns it would take to prevent the spread of HIV. The OTA report said the government had shirked its responsibility at least partly because providing

²⁷⁴. Marvin E. Bailey, “Community-based Organizations and CDC as Partners in HIV Education and Prevention,” *Public Health Reports* 106 (1991):702-8.

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advice on preventive sex practices might be viewed as “condoning the lifestyles” of homosexuals.²⁷⁵

Conservative Reaganites weren’t the only ones in the government obstructing efforts to do anything useful to prevent the spread of HIV. Dr. David Sundwall, described in *Mother Jones* as “a clean-cut Mormon physician,” was the physician adviser to the Senate Committee on Labor and Human Resources before becoming the administrator of the Health Resources and Services Administration. In early 1985, Sundwall described memos that had been issued from some Republican committee members’ offices. “I don’t want to name names,” he said, “but I can tell you that the most blatant kind of homophobia possible is indicated in these memos. Very judgmental, very negative statements questioning whether the government should play any role whatsoever in [stopping the disease]—it’s probably God’s wrath and so be it.”²⁷⁶

To avoid scrutiny of its prevention funding by the radical right and its supporters in the White House and on Capitol Hill, CDC in 1985 funneled seed money to community-based organizations through the US Conference of Mayors. The USCM at the time represented about 860 cities, which accounted for 90 percent of the nation’s reported AIDS cases. The organizations funded by USCM were required to collaborate with state and local public health departments, and to generate community cooperation and support for AIDS prevention activities—a dubi-

²⁷⁵. US Congress, Office of Technology Assessment, *Review of the Public Health Service Response to AIDS* (Washington, DC: OTA, 1985).

²⁷⁶. David Talbot and Larry Bush, “At Risk,” *Mother Jones* (April 1985), 29-37.

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ous prospect for prevention efforts targeting gay men, in view of the antigay attitudes even among the nation's elected leaders.

Alan Gambrell, who in January 1985 became the first full-time staffer in USCM's AIDS program, recalled that one early prevention effort supported by USCM with CDC funds was a safe-sex brochure developed by AID Atlanta, a gay community-based AIDS organization in the CDC's own hometown. When an article about the brochure appeared in USCM's newsletter, Gambrell said there was "some negative feedback from a small number of mayors," including the resignation from USCM of one mayor of a small Texas city. Gambrell also noted that there were already "rumblings" from anti-gay North Carolina Senator Jesse Helms about the content of educational materials directed at gay men.²⁷⁷

From June 4 to 6, 1986, some eighty-five clinicians, epidemiologists, public health policy-makers, and basic research scientists gathered at the Coolfont Conference Center in Berkeley Springs, West Virginia. Convened by the Public Health Service, their task was to review the government's plan for preventing the spread of AIDS by the year 2000. At that point there were already 20,517 AIDS cases reported in the United States. By the end of 1991, the group estimated, upwards of 30 percent of the one million to one-and-a-half million Americans believed to be infected with HIV would develop AIDS, bringing the cumulative death toll to more than 179,000. More than 70 percent of the cases would be diagnosed among gay and bisexual men, they predicted, though increases in AIDS among heterosexuals were "likely." They didn't expect a possible vaccine for at least a decade, despite HHS Secretary Margaret Heckler's promise two years earlier of a vaccine within two years.

²⁷⁷. Alan E. Gambrell, interview with author, Washington, DC, 25 February 1995.

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“In the absence of a vaccine and therapy,” noted the Coolfont Report, “prevention and control of HTLV-III/LAV infection [as HIV was known at the time] should be targeted to individuals and groups whose behavior places them at high risk for AIDS, other sexually active adults, adolescents, preadolescents, and health care providers.” Further, it recommended, “With the assistance of appropriate organizations, programs should be implemented to provide culturally sensitive, meaningful information and education to Blacks and Hispanics, including homosexuals.”²⁷⁸

The news from Coolfont was overshadowed by a Justice Department legal opinion on June 23, 1986. Attorney General Edwin Meese determined that an employer could legally fire employees with AIDS—or even those perceived as having the disease—if other employees feared “catching” it.

A week after Justice’s decision, the Supreme Court dealt a crushing blow to the gay civil rights movement in the landmark case *Bowers v. Hardwick*. In a five-to-four majority, the Court ruled that gay people were not constitutionally entitled to privacy and could be prosecuted for making love in their own bedrooms. As Lisa Keen noted in the *Washington Blade* on the tenth anniversary of the decision, “The *Hardwick* decision was used to impeach every gay person’s character, whether they engaged in sodomy or not and in areas that had nothing to do with oral and anal sex at all. Its impact, like that of sodomy laws

²⁷⁸. Coolfont Report: A PHS Plan for Prevention and Control of AIDS and the AIDS Virus,” *Public Health Reports* 101 (July–August 1986): 341-48.

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themselves, delivered both a powerful quake and a more devastating series of aftershocks.”²⁷⁹

In New York, the Justice Department and Supreme Court decisions couldn't have come at a more ironic time. In March, fifteen years after it was introduced, the New York City Council finally passed an ordinance to protect gay people against discrimination in jobs and housing. Mayor Koch told reporters, “The sky is not going to fall. There isn't going to be any dramatic change in the life of this city.”²⁸⁰ For gay New Yorkers, though, merely knowing they had legal recourse in the event they were discriminated against was a tremendous change and a great improvement in the city's quality of life.

Arnie Kantrowitz celebrated the adoption of the new ordinance he and other members of Gay Activists Alliance first lobbied for in 1971. Kantrowitz thought the measure's passage by a vote of 21 to 14 was due to the growing awareness of the public and politicians of who gay people really were as they rallied in response to, and died in incredible numbers from, AIDS. Kantrowitz observed, “Possibly some of the attacks on the ailing gay community had generated enough sympathy to gather the required votes, but most of it was politics.”²⁸¹

Two major reports in late 1986 echoed the recommendations from Coolfont. In his unexpectedly forthright report, Sur-

²⁷⁹. Lisa Keen, “Hardwick Revisited.” *Washington Blade* (5 July 1996), 1.

²⁸⁰. Leigh W. Rutledge, *Gay Decades* (New York: Penguin Books, 1992), 254.

²⁸¹. Arnie Kantrowitz, *Under the Rainbow: Growing Up Gay* (New York: St. Martin's, 1996), 206.

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geon General C. Everett Koop said, “We can no longer afford to sidestep frank, open discussions about sexual practices—homosexual and heterosexual.”²⁸² The prestigious Institute of Medicine, part of the National Academy of Sciences, noted in its own report, *Confronting AIDS*, “The present level of AIDS-related education is woefully inadequate.” The panel of prominent researchers and clinicians who developed the report observed that “in general the only efforts with any claim to success have been those conducted by homosexuals through voluntary activist organizations.”²⁸³

In October, the federal government mailed a brochure called *Understanding AIDS* to every American household, offering less explicit information about AIDS and how to prevent it than Americans could get from their daily newspapers at that point. Meanwhile, President Reagan that month suggested at a White House meeting that Libyan dictator Moamar Gadhafi, rumored to enjoy dressing in drag, should be sent to San Francisco because “he likes to dress up so much.” Secretary of State George Shultz diplomatically added, “Why don’t we give him AIDS?” As fear gripped the nation, and although thousands of

²⁸². C. Everett Koop, MD, Surgeon General, “Introductory Statement, Report on AIDS” (Rockville, Md.: US Government Printing Office, 22 October 1986).

²⁸³. Institute of Medicine/National Academy of Sciences, *Confronting AIDS: Directions for Public Health, Health Care, and Research* (Washington, DC: National Academy Press, 1986), see especially 95-105.

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Americans were dead from AIDS, the epidemic was treated as a sick joke at the White House.²⁸⁴

Ignoring the recommendations of the nation's leading medical and public health experts in the three major reports in 1986, the CDC that very year went berserk after Gay Men's Health Crisis allegedly used federal funding to produce a video that presented explicit gay sex—albeit with condoms—as part of the agency's prevention program. GMHC considered the video to be precisely the kind of “targeted, explicit” educational tool it needed, and that CDC would support, to teach gay men. Gay men presumably would understand the safe-sex message the video conveyed, and emulate what it depicted in their own sex lives. Its use of familiar language provided a safe-sex vocabulary that GMHC hoped would prove useful in real-life sexual negotiations. As the late social worker Michael Shernoff put it, “For safer sex education to go on, you have to have it happen in a context that's recognizable to the people who are involved. People are more likely to talk about ‘dicks’ and ‘cum,’ as opposed to ‘penis’ and ‘semen.’ I don't know anyone who thinks about sex as ‘anal intercourse’ except the doctor—and he's not the one getting fucked.”²⁸⁵

CDC prohibited the further development of explicit, “offensive” materials, and required that anyone getting funding to

²⁸⁴. SF Anger Over ‘Jokes’ at White House,” *San Francisco Chronicle* (3 October 1986). Noted in James Kinsella, *Covering the Plague: AIDS and the American Media* (New Brunswick, N.J.: Rutgers University Press, 1987), 3.

²⁸⁵. Quoted in Nicholas Freudenberg, *Preventing AIDS: A Guide to Effective Education for the Prevention of HIV Infection* (Washington, DC: American Public Health Association, 1989), 115.

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produce HIV prevention materials had to establish local review panels to screen the materials.²⁸⁶ This requirement was precisely what the Institute of Medicine advised against when it said it was “concerned about the Centers for Disease Control directive that empanels local review boards to determine whether materials developed for AIDS education are too explicit and in violation of local community standards”—what it called “the ‘dirty words’ issue.”²⁸⁷ Such oversight panels meant that prevention targeted at gay men would have to pass muster with the nongay people who would participate in these review panels. It didn’t take genius to see the direction this would take.

Despite the gutting of anything like effective prevention, Health and Human Services Secretary Otis Bowen said he would be “disappointed” if public education efforts were not effective within a year. As *Newsweek* noted, “The bottom line: the Reagan administration, like most Americans, is betting on a scientific breakthrough to deliver America from the epidemic.”²⁸⁸ But Reagan’s sentimental rhetoric about its being “morning in America” aside, his pandering to the far right, combined with his evisceration of the nation’s health and scientific research institutions, meant that even America’s world-renowned scientists couldn’t hold back the encroaching plague.

“Federal prevention programs have been in almost total disarray the last few years,” said AIDS Action Council director

²⁸⁶. Julie Kosterlitz, “Educating About AIDS,” *National Journal* (30 August 1986), 2044.

²⁸⁷. Institute of Medicine, *Confronting AIDS* (Washington, DC: National Academy Press, 1986), 99.

²⁸⁸. Tom Morganthau et al., “Future Shock,” *Newsweek* (24 November 1986), 30-39.

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Gary MacDonald in a lengthy *U.S. News & World Report* article in January 1987. While the Institute of Medicine report had recommended that the federal government increase its AIDS funding by five times—to \$2 billion in fiscal 1990, with money divided equally between education and research—less than one-quarter of the government’s funds went to prevention at the time of the report’s release. The Reagan administration saw no need to increase its funding for prevention for this particular disease. Ken South, then the director of AID Atlanta, the group that had received \$12,500 from the CDC through the U.S. Conference of Mayors, noted that the meager amount of funding the agency received had come with a mandate “to change the most intimate behavior of one hundred thousand people at risk.” As South put it, “We’re trying to put out a forest fire with a water pistol.”²⁸⁹

At the CDC itself, Don Francis was thwarted at every turn in his efforts to get the government to provide serious prevention education. His requests for additional funding were repeatedly turned down. Francis told me, “I was in Atlanta, sandwiched between CDC’s philosophy of aggressive public health and the Reagan Administration. And I was literally told, when I made the first plan for HIV prevention for the U.S., for \$37 million—a small amount of money—that we couldn’t afford that, and to ‘look like you’re doing something, but we can’t get into that prevention stuff for this disease.’”²⁹⁰

Even when I interviewed him in the mid-nineties, Francis’s blood still boiled the way it did when he testified before a congressional committee on March 16, 1987, saying, “Much of the

²⁸⁹. McAuliffe et al., “AIDS: At the Dawn of Fear.”

²⁹⁰. Donald P. Francis, MD, Ph.D., interview with author, Washington, DC, 9 February 1995.

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HIV/AIDS epidemic was and continues to be preventable. But because of active obstruction of logical policy, active resistance to essential funding, and active interference with scientifically designed programs, the executive branch of this country has caused untold hardship, misery, and expense to the American public. Its effort with AIDS will stand as a huge scar in American history, a shame to our nation and an international disgrace.”²⁹¹

As if to underscore Francis’s point, President Reagan finally delivered his first speech on AIDS two months after that hearing—*six years* into the epidemic. He called for “routine” HIV testing of certain groups, including immigrants, federal prisoners, and applicants for marriage licenses. Despite the recommendations from Coolfont, the Institute of Medicine, and his own surgeon general, Reagan saw widespread testing as the answer to the nation’s utter lack of a concerted AIDS prevention program. The *New York Times* said, “Mr. Reagan’s Administration has been slow to respond to the AIDS epidemic, yet its first thought is to compel testing. That is inconsistent with what public health officials advise and with the compassion evident in Mr. Reagan’s words.”²⁹²

Compassion was not a quality usually associated with the Reagan administration when it came to AIDS (or much else). It

²⁹¹. “The Federal Response to the AIDS Epidemic: Information and Public Education,” hearing before a subcommittee of the Committee on Government Operations, House of Representatives, 16 March 1987. Noted in *The Politics of AIDS Prevention: Science Takes a Time Out*, report of the Committee on Government Operations, US House of Representatives. (Washington, DC: US Government Printing Office, 1992).

²⁹². Unsigned editorial, “Mr. Reagan’s AIDS Test,” *New York Times* (2 June 1987).

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would prove to be in even shorter supply—with rational thinking scarcer still—when Republican Senator Jesse Helms delivered a diatribe that will go down in history as one of the most hate-filled, yet amazingly persuasive, speeches ever delivered in the U.S. Senate.

A mere three days after an estimated 650,000 gay people and their supporters participated in the second National March on Washington for Gay and Lesbian Rights, and the premiere display of the AIDS Memorial Quilt on the National Mall, Helms took to the Senate floor on October 14, 1987, waving a copy of GMHC's "Safe Sex Comix." He threatened to "throw up" after viewing the booklet and video, which illustrated safe-sex techniques for gay men. GMHC had developed the materials based on a study of eight hundred gay men, which found that frank, explicit prevention information worked best for gay men—just as the CDC and all those official reports had recommended.

But Helms, never one to miss an opportunity to show his bigoted ignorance, claimed the materials had been funded by taxpayer dollars, and condemned them as "pornographic." Rather than protecting the lives of gay men, as the materials were intended to do, the senator said they merely promoted "safe sodomy." Helms succeeded in convincing ninety-eight of the Senate's one hundred members to support his amendment to the Labor, Health and Human Services and Education Appropriations Bill. The amendment prohibited the use of federal funds for any AIDS educational materials that "promote or encourage, directly or indirectly, homosexual sexual activities."

Senators Ted Kennedy and Alan Cranston were the only ones to oppose Helms. Kennedy successfully reworded the amendment in committee so it would disallow the promotion of sexuality in general, rather than homosexuality in particular. But

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the damage was already done. For Helms, talking about homosexuality was tantamount to promoting it.

Gay activists naturally dubbed the Helms amendment “No Promo Homo.” But how could anyone possibly talk about protection against a deadly sexually transmitted disease without talking about sex? About a disease largely affecting homosexuals without talking about homosexual sex?

As if it hadn’t been made all too clear all too many times in the epidemic, the fallout of the Helms amendment meant that if gay men were going to be educated about protecting themselves, the gay community would have to do the job itself. Although homosexual Americans pay taxes like everyone else, it became apparent in 1987 that they would also have to pay for their own AIDS education if they hoped to stem the tide of new HIV infections among the nation’s hardest-hit group. That is to say that a subcommunity, totaling at best 10 percent of the population, would be expected to carry the burden of fighting the greatest health threat of the century in the wealthiest, most medically sophisticated nation on earth.

FOURTEEN

Still hoping to look as though it had the AIDS epidemic under control, the CDC, through the U.S. Conference of Mayors, began in 1987 to award HIV education and prevention funds almost exclusively to community-based racial and ethnic minority organizations.²⁹³ In what would define CDC's skewed approach to AIDS education for people of color, a report on the new efforts targeting minorities said, "Although homosexual and bisexual contact is a major mode of HIV transmission among Blacks and Hispanics, intravenous drug use and heterosexual contact are more prevalent modes of transmission for them than for whites."²⁹⁴ While it noted correctly that 70 percent of heterosexuals, 70 percent of women, and 75 percent of children [with AIDS] were Black or Hispanic, the report failed to mention that the number of gay and bisexual men with AIDS in the country's minority communities far surpassed the number of heterosexuals, women, and children with the disease.

FOURTEEN

²⁹³. Priscilla B. Holman et al., "Increasing the Involvement of National and Regional Racial and Ethnic Minority Organizations in HIV Information and Education," *Public Health Reports* 106 (November–December 1991): 687-94.

²⁹⁴. Jacqueline Bowles and William A. Robinson, "PHS Grants for Minority Group HIV Infection Education and Prevention Efforts," *Public Health Reports* 104 (November–December 1989): 552-59.

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There was an odd assumption on everyone's part that somehow intravenous drug users were all Black or Hispanic, and that all homosexuals were white. By not challenging this assumption, countless gay men of color were sacrificed in order to placate the homophobes—only this time the skin color of those homophobes was darker than that of Jesse Helms.

At a 1988 conference organized by the Department of Health and Human Services to shape a prevention agenda for minority communities, Black, Hispanic, Native American, and Asian/Pacific Islander caucuses defined what they felt were the major considerations for prevention education in their respective communities. The report from the Black caucus in particular was permeated with fear that African-Americans would be “blamed” for the AIDS epidemic because of its suspected origins in Africa, and by the paranoid belief that Blacks had been targeted for genocide by research scientists who “have exposed the race to a deadly ‘Andromeda Strain.’” Of course white gay men had their own conspiracy theories early in the epidemic. Reading the caucus report, though, one wouldn't know that homosexuality even existed in the Black community or that Black gay and bisexual men accounted for most of the community's AIDS cases—as neither fact is ever mentioned.

The caucus said “the Black community” was resolved “to look to our Black clergy and church for absolute assurance that CDC national AIDS testing and counseling initiatives are not just another Tuskegee tragedy being perpetrated on the Black race.” The group feared, not altogether irrationally, a repeat of the infamous government-sponsored syphilis studies that, in a page from the Nazis' own playbook, had allowed Black men in Alabama to remain untreated as a means of observing the course of the disease. As for prevention, they said, “We not only categorically reject, but also deem offensive, all AIDS literature and advice that teach and promote sexual practices and

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behaviors that offend the cultural integrity of the Black race and go against the teachings of our church and religious beliefs."²⁹⁵ Strangely enough, the Black caucus included several well-known black gay activists whose voices, one charitably assumes, were not heard by the rest of the group.

Overlooked by CDC and the white gay community, and ignored by their own community, it was clear that Black gay men and other men of color—like their white gay brothers—would have to educate themselves. Fortunately, Black gay men had a bold and visionary leader in Reggie Williams, who recognized early on that the only way gay men of color would survive the epidemic was to mount their own educational campaigns. In 1984, Williams was a member of the San Francisco chapter of Black and White Men together (BWMT), a nationwide network of social support and advocacy organizations. After a presentation at a BWMT meeting to representatives of several AIDS organizations serving people of color, Williams offered to host another meeting at his home the following week for anyone interested in talking about the AIDS-related concerns of gay men of color. This would be the first meeting of what became the AIDS task force of BWMT/San Francisco, a group dedicated to advocating on behalf of gay men of color for services in the city.

Pulling together the AIDS efforts of other BWMT chapters under the auspices of the National Association of Black and White Men Together, Williams in 1988 won a contract from the CDC to provide AIDS prevention to gay men of color. Reflecting on those years in a telephone interview from his home in Amsterdam, where he was living with both his German lover and

²⁹⁵. Department of Health and Human Services, Office of Minority Health, *Prevention and Beyond: A Framework for Collective Action* (A National Conference on HIV Infection and AIDS Among Racial and Ethnic Populations), 1989.

VICTORY DEFERRED

AIDS, Williams recalled saying to himself, “If they’re not going to do it [prevention for gay men of color], then goddamn it, we can do it for ourselves. We’re not crippled! We have power. That’s why we created the National Task Force on AIDS Prevention—to do it for ourselves.”

From its inception, the task force brought together gay men of color—including African-Americans, Hispanics, Native Americans, and Asian/Pacific Islanders—to advocate on their own behalf and devise ways to reach other gay men like themselves who felt they were not being served adequately by either gay or “mainstream” organizations in their communities. The group believed strongly that for gay men of color to be receptive to AIDS prevention messages, they would need to get those messages from other men who “looked like” them. As Williams put it, “The messenger is just as important as the message.”

For Williams, “doing for ourselves” began with honesty about one’s identity—in terms of race, sexual orientation, and even HIV antibody status. He described the liberation he felt personally because of such frankness. “I was able to walk up to the podium and say, ‘I’m Reggie Williams, a Black gay man with HIV,’ instead of saying, ‘I’m Reggie Williams, executive director of the National Task Force on AIDS Prevention.’” And it always had an effect on the audience, said Williams, “whether hetero, gay, white, or Black.” He explained, “I didn’t look like most people’s idea of a person with HIV/AIDS since I wasn’t dragged in or wheeled out to the podium.”²⁹⁶

Besides promoting a sense of gay pride, the task force realized that prevention education targeted to gay men of color had to build upon and support a man’s sense of cultural identity—

²⁹⁶. Reginald Williams, telephone interview with author, 25 August 1995.

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including loyalty to his family, racial or ethnic community, and religious faith. The organization understood that gay men of color face what Williams called a “double-edged sword”—torn as they often are between their sense of belonging to the (largely white) gay community and their racial or ethnic community, and not fully accepted in either. For this reason the task force viewed its role as largely that of building self-esteem so that gay men of color would be motivated to protect themselves and one another against HIV. As Randy Miller, Williams’s successor at the National Task Force, explained, the key to the agency’s unique workshops and media campaigns was to use the community and family loyalty of gay men of color as a jumping-off point, “tying a sense of cultural survival to individual survival.”²⁹⁷

The operating philosophy of the organization, which, until its 1998 closing because of fiscal mismanagement, was the nation’s largest prevention and advocacy agency working specifically on behalf of gay men of color, was handed down directly from the life of its founder. As Williams said, “I know what it is to have low self-esteem and not feel like your life has value; I’ve been there. I grew up in the ghetto, so I know what it’s like.”²⁹⁸

Beginning in the late eighties, there was constant talk about “the changing face” of the AIDS epidemic. In 1987, *Time* magazine put it this way: “The face of AIDS in America is changing; it is getting younger, darker, more feminine.”²⁹⁹ But the rates of

²⁹⁷. Randy Miller, interview with author, San Francisco, 31 January 1995.

²⁹⁸. Williams interview.

²⁹⁹. Richard Stengel, “The Changing Face of AIDS,” *Time* (17 August 1987), 12-14.

VICTORY DEFERRED

AIDS and HIV infection in the Northeast skewed the national figures on the epidemic because the region has the highest incidence of HIV and AIDS among female sexual partners and their children. Outside the Northeast, particularly New York and northern New Jersey, the “main epidemic” (there are several different epidemics in the US, including, for example, a rising epidemic among Black women in the South) is still among gay and bisexual men of all races and ethnicities.³⁰⁰

What’s more, gay and bisexual men of color still account for both the largest proportion of cases among racial and ethnic minorities as well as a growing percentage of the cases among gay and bisexual men in general. By 1993 in Chicago, for example, 69 percent of the AIDS cases among African-American men were among gay and bisexual men, some of whom were also injection drug users. In Los Angeles, 76 percent of the AIDS cases among African-American men, 80 percent among Hispanic men, and 86 percent among Asian and Pacific Islander men involved homosexual contact.³⁰¹

In spite of the large numbers of gay men of color affected by AIDS—a third of the cumulative total of AIDS cases among those whom the CDC calls “men who have sex with men”—funding for prevention programs targeting them ranged from a paltry 1 to 13 percent of the total city and county prevention funds in five major cities described in a 1993 report by the US

³⁰⁰. Lawrence K. Altman, “Obstacle-Strewn Road to Rethinking the Numbers on AIDS,” *New York Times* (1 March 1994), C3.

³⁰¹. Richard Tagle and Gil Gerald, *Assessing the HIV Prevention Needs of Gay and Bisexual Men of Color* (Washington, DC: US Conference of Mayors, 1993).

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Conference of Mayors.³⁰² As the National Commission on AIDS noted in its own report a year earlier, *The Challenges of HIV/AIDS in Communities of Color*, “Serious questions have been raised as to whether the populations most at risk for AIDS within communities of color are being appropriately targeted.” The commission noted that although half of African-American and Hispanic male adults with AIDS at the time were men who have sex with men, services in communities of color are often not designed to reach them. Because the same could be said of predominantly white gay organizations, the commission concluded, “gay men of color are frequently left in limbo.”³⁰³

As a result, the number of AIDS cases among Black and Hispanic gay men continued to rise from the late eighties through the nineties. By the middle of 1997, there had been 612,078 AIDS cases reported in the United States. Of these, 298,699 were among men who were infected with HIV through sex with another man; an additional 39,923 men had sex with men and injected drugs. Together, these two groups accounted for well over half of all the nation’s AIDS cases. Of them, 214,427 were white, 74,140 Black, and 44,680 Hispanic.

Contrasting these numbers to the rates of AIDS among women and children provides a study in the politics of prevention—and would seem to suggest that the lives of gay and bisexual men are valued far less than those of women and children. Consider: In 1995, men with no other risk factor than sex with another man *alone* accounted for more than three times the total number of women with AIDS—and nearly thirty-eight

³⁰². Ibid.

³⁰³. National Commission on AIDS, *The Challenge of HIV/AIDS in Communities of Color* (Washington, D.C.: National Commission on AIDS, 1992).

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times the total number of children with AIDS.³⁰⁴ Yet, in the state of California, for example, a study of funding for HIV prevention found that although gay men comprised 88 percent of the state's AIDS cases, prevention efforts targeting gay men accounted for a mere five percent of the state's prevention money.³⁰⁵ Nationally, the Gay and Lesbian Medical Association estimated that less than 5 percent of all prevention funding in this country targeted gay men.³⁰⁶

The belief obviously persisted that gay men can and should take care of themselves, fund their own prevention efforts, and not expect a share of public prevention dollars commensurate with their rates of infection and disease.

When the surgeon general's report on AIDS was updated in 1993, gay men were described—and dismissed—on page 1 like this: "In this second decade of the AIDS epidemic, *gay men still account for the majority of AIDS cases reported each year* [my italics] and continue to suffer an enormous burden. However, AIDS is becoming more prominent in the young and in heterosexual women and men." After that "however," gay men are never again mentioned in the next twenty-five pages of the report. Instead, it focuses exclusively on heterosexuals, women, children, and teenagers—without even acknowledging the fact that two-thirds of male adolescents with AIDS are in-

³⁰⁴. Centers for Disease Control and Prevention, *HIV/AIDS Surveillance Report* 7(2) (1995): 10.

³⁰⁵. Thomas J. Coates and Pamela DeCarlo, "Fifteen Years Later, Prevention Still Falls Short," *Washington Blade* (28 June 1996), 39.

³⁰⁶. "HIV Prevention Efforts Fall Short," *San Francisco Sentinel* (29 March 1995), 18.

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fectured with HIV through homosexual behavior.³⁰⁷ A CDC catalog of HIV and AIDS education and prevention materials produced the same year doesn't mention gay men even once.³⁰⁸

In the private sector, in 1998 (seventeen years into the epidemic), the table of contents for the on-line service AEGIS (AIDS Education Global Information Network), which billed itself as "the largest HIV/AIDS database in the world," never mentioned gay men. It did, however, include women, children, and "other," a category that, it explained, encompassed the visually

³⁰⁷. *Surgeon General's Report to the American Public on HIV Infection and AIDS* (Rockville, Md.: U.S. Government Printing Office, June 1993), 1.

³⁰⁸. CDC National AIDS Clearinghouse, *Catalog of HIV and AIDS Education and Prevention Materials* (Washington, D.C.: US Department of Health and Human Services, January 1993).

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impaired, the deaf, the developmentally disabled, and racial minorities.³⁰⁹

CDC's longstanding "offensiveness" standard—going back to its 1986 crackdown on explicit prevention materials targeting gay men—was overturned by a federal district court in May 1992. GMHC was vindicated in its claim that the "Safe Sex Comix" that so upset Jesse Helms was not paid for with public funding. "But," noted a congressional report on federal prevention efforts, "CDC, not to be outdone, the following month issued new requirements that order program review panels to ensure that CDC funds are not used for prevention materials considered to be 'obscene.'" As a reminder of the "chilling effect" lingering from the Helms amendment," the report continued, "The CDC's directive continues to require the review panels to ensure that prevention materials do not 'promote or en-

³⁰⁹. An Internet search on 4 March 1998 found that AEGIS, at aegis.com, listed every "group" of people at risk for or affected by HIV/AIDS, except "men who have sex with men," as the CDC designates gay and bisexual men. AEGIS operated as a religiously affiliated, nonprofit California organization. When I inquired about this startling omission, given the epidemiology of the epidemic in the US, I was barraged with e-mail messages from Rick M. Wagner and someone else at AEGIS called "Wynn." In a message dated 4 May 1998, Wagner wrote: "Unfortunately to those people who need to see the words GAY, HOMOSEXUAL, QUEER (whatever) plastered all over the web site, I can only suspect that the topic of HIV/AIDS is secondary to their own sexual identity." Both men identified themselves as gay, yet they dismissed my questions and defended themselves vociferously in personal, patronizing attacks. They threatened me with a libel suit for "defaming" what Wagner called their "great service."

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courage directly homosexual or heterosexual activity or intravenous substance abuse.”³¹⁰

Throughout the nineties, CDC continued to be told that it needed to target AIDS prevention education to those who needed it most. According to its own epidemiological reports, that largely should have meant gay and bisexual men, intravenous drug users and their partners.

In 1993, an eight-month investigation of CDC’s HIV prevention program—representing about 85 percent of its \$539 million AIDS budget at the time—recommended, yet again, that the government’s public education should offer explicit information on how HIV is transmitted and on the value of condoms in disease prevention.³¹¹

Scientists also were urging that prevention education focus on people at the highest risk in the nation’s hardest-hit areas—some twenty-five to thirty neighborhoods altogether in cities that included Camden, N.J., Houston, Los Angeles, Miami, Newark, N.J., New York City, and San Francisco. In a front page *New York Times* story, Dr. John Gagnon, a sociologist at the State University of New York at Stony Brook, was quoted as saying, “We’ve got to put the money where the problem is, instead of spreading it around in a Johnny Appleseed way.”³¹²

³¹⁰. Sari Staver, “CDC Advised to Refocus Its HIV Prevention Efforts,” *American Medical News* (13 December 1993), 10.

³¹¹. Ibid.

³¹². Gina Kolata, “Targeting Urged in Attack on AIDS,” *New York Times* (8 March 1993), 1.

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Did the government listen? Had it ever, really? Instead of targeted, explicit prevention education that might actually work to save the lives of Americans by telling them forthrightly how to protect themselves against HIV, the government continued its scattershot approach—targeting everyone in general, no one in particular, and offering only emotional appeals aimed at “raising awareness.” Of course most Americans already were quite aware of AIDS, though not all of them viewed their own behavior as risky because the government’s vaguely worded educational programs gave them multiple opportunities to deny their own risk.

Although they already had been widely criticized as too vague and ineffectual, CDC in 1992 launched yet another round of its “America Responds to AIDS” print and broadcast ads. Announcing the new ads at a press conference, Assistant Secretary for Health James Mason denied that political pressure had forced the government to produce conservative ads. Yet he stunned the audience when he said, “There are certain areas [in] which, when the goals of science collide with moral and ethical judgment, science has to take a time out.”³¹³ It seemed science had been given a permanent hiatus by the nation’s leading disease prevention institution.

The latest round of “America Responds to AIDS” ads maintained the government’s unswerving commitment to avoid controversy at all costs. But besides the hundreds of millions of taxpayer dollars wasted on efforts considered by experts to be useless, the costs of delaying an effective educational program included the very lives of those who would become infected with HIV because politically beholden bureaucrats refused to allow frank discussion of sexuality and drug use.

³¹³. US House of Representatives, “The Politics of AIDS Prevention: Science Takes a Time Out” (1992).

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Instead of useful messages, we got more pabulum. For instance, after an “America Responds to AIDS” message—designed, as Mason put it, to “convey personal meaning about the tragedy of AIDS”—viewers were told they could “find out how you can prevent HIV” by calling the CDC’s AIDS hotline.³¹⁴ The ad never once told viewers how, exactly, to protect themselves. In fact, condoms are never once mentioned in the ads. Instead “abstinence” remained the sine qua non of the government’s prevention message: If you want to protect yourself from getting AIDS, don’t have sex or shoot drugs. It’s as simple—and simplistic—as that. If you do have sex or shoot drugs, you’re on your own. Jeff Levi said of the ads, “You don’t sell things by stating an 800 number. If you’re selling laundry detergent, you don’t say, ‘Are you concerned about dirty laundry? Call 1-800-DETERGENT.’”³¹⁵

Why was the government so singularly spineless in its efforts to prevent the spread of HIV? Quite simply, because all those years, and nearly two-thirds of a million AIDS cases since the start of the epidemic, the government remained hobbled by its fear of upsetting Jesse Helms and his antisex, antigay compatriots at the outer fringe of the right wing.

Instead of forthright discussion of the behaviors that put an individual at risk, and the explicit, targeted messages recommended by every scientist and medical expert working on AIDS in this country, what the *New York Times* called a “deathly silence” about sexuality continued to reverberate throughout the

³¹⁴. Laurie Jones, “New Ads Say AIDS Can Hit Anywhere,” *American Medical News* (13 April 1992), 3.

³¹⁵. Ibid.

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government's prevention programs.³¹⁶ As politicians continued to placate religious bigots, gay men—as well as women, adolescents, and injection drug users—continued to become infected and die.

³¹⁶. Unsigned editorial, "A Deathly Silence," *New York Times* (2 August 1994).

FIFTEEN

The Stop AIDS Project reopened in 1990 because of the rising incidence of unprotected sex and new HIV infections among gay men in San Francisco. When the project closed three years earlier, its efforts to quickly change the way gay men had sex by making safe sex the norm seemed to have paid off, as the rate of new HIV infections and reports of unsafe sex declined. Everyone celebrated, prematurely as it turned out, what they believed was the community's adoption of safe sex—including the “normalization” of condoms. It seemed the gay community had accomplished a feat never before seen in the history of public health: Through their own efforts, gay men on a wide scale seemed to have heeded the warnings about AIDS and modified their behaviors accordingly.

But as the years passed and the epidemic wore on, fear alone didn't suffice to prevent some men from having unsafe sex. Researchers puzzled over what was driving them to do it, despite the gay community's high awareness of AIDS and what is and isn't safe. In the same way as serious scientists wondered in the earliest years of the epidemic what unique quality in gay men made them particularly susceptible to AIDS, they now wondered why some gay men, a decade after the epidemic began, were returning to the sexual behavior they had practiced before safe sex allegedly became the “norm.” Among the reasons suggested, one study said that a “high subjective gratification derived from past risky sexual practices” was a major

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predictor of unsafe activity.³¹⁷ Put simply, those who enjoyed the kind of sex they practiced before the epidemic—or at least until they presumably began to practice safe sex—were “at risk” for engaging in sexual behavior, now proscribed, which they obviously enjoyed and that was natural for them. If ever common sense observation had been gussied up as science, this was it.

A 1993 article in the *New York Times* shocked both San Francisco and the nation when it reported that a “second wave of AIDS” was feared and forecast in San Francisco. One out of every fifty gay men in the city was becoming infected each year—twice that number among men under twenty-five. Although the rate was a considerable drop from 1982, when eighteen gay men in 100 were infected annually, it was climbing again from its 1985 nadir.³¹⁸ Researchers, many gay men, and heterosexuals alike wondered: Why did these men put themselves at such risk? Didn’t they know better? Did they have a death wish?

As everyone argued and finger-pointed their way to an answer, San Francisco therapist Tom Moon pointed out something so obvious as to have eluded everyone: prevention isn’t simply a matter of knowing how to have safe sex. “People have emo-

³¹⁷. Jeffrey A. Kelly, Janet S. St. Lawrence, Ted L. Brasfield, “Predictors of Vulnerability to AIDS Risk Behavior Relapse,” *Journal of Consulting and Clinical Psychology* 59 (1991): 163–66.

³¹⁸. Jane Gross, “Second Wave of AIDS Feared by Officials in San Francisco,” *New York Times* (11 December 1993).

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tional lives,” said Moon. “They’re not just information-processing machines.”³¹⁹

Moon was on to something no one had taken into account as they planned and launched campaigns aimed at changing the way gay men think about and engage in sex. After a decade of an epidemic that was expected to have ended years before (and still no cure in sight), thousands of deaths, countless hours spent at hospital bedsides and memorial services, it finally began to dawn on prevention professionals that years of loss, grief, and self-denial were eating away at the resolve of gay men to protect themselves in order to survive the epidemic.

Stop AIDS Project’s then-prevention director Daniel Wohlfeiler said, “What happens when survival becomes a very iffy concept? When five of your boyfriends have died? When fifty of your closest friends have died? When people you do business with every day, the people you dance with, all the people you wanted to survive with—aren’t there anymore? It wears down the resolve so that when push comes to shove, the decision of whether to put the condom on or not is not so clear-cut anymore.”³²⁰

Researchers recommended that prevention efforts shift from focusing only on getting men to have safe sex, to a longer-term strategy that emphasized the maintenance of safe sex—assuming, of course, that it had been adopted in the first place. Finally, prevention educators were beginning to realize that knowledge alone isn’t enough to make people protect themselves. Only now were researchers noting, forebodingly, that

³¹⁹. Ibid.

³²⁰. Michael Munzell, “Dancing with Death,” *Image* (23 August 1992), 23–27.

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studies on other behaviors—smoking cessation, alcohol abstinence, and dieting—had shown that it is extremely difficult to maintain healthy behaviors over time. At the national gay and lesbian health conference in 1993, held that year in Houston, David Ostrow said, “Information alone is not going to be enough to maintain safer sexual behavior. People have a tendency to go back to learned, pleasurable behaviors.”³²¹ Leon McCusick made the same point a decade earlier. Had anyone listened?

But gay men are hardly unique in this regard. When it comes to sex, most people are hedonistic by nature and the sternest of warnings will not suffice to deter everyone from pleasurable activities all the time, particularly in an emotionally intimate relationship. As Abraham Verghese, a heterosexual AIDS doctor put it, “No cerebral abstraction involving sex—whether it was the need for contraception, proscriptions against adultery, or the need for safe sex—had ever in human history fared well in the face of raw lust.”³²²

Lust and the irrational desires and needs that drive most of us sexually were not really taken into account when educators conceived of prevention programs for gay men in the eighties. They figured that if the men knew about AIDS and how to protect themselves from getting HIV, they’d naturally do so—100 percent of the time.

But no one in 1986 expected the epidemic to last as long as it has done, or to practice safe sex longer than absolutely nec-

³²¹. John-Manuel Andriote, “Gay Men and Unsafe Sex,” *Washington Post*, “Health” supplement (10 August 1993).

³²². Abraham Verghese, *My Own Country: A Doctor’s Story* (New York: Vintage Books, 1994), 133.

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essary. By the nineties, gay men were tired of AIDS, worn down by grief, and questioning the authority of prevention educators. When had they become such “authorities” anyway? Rather than directing people to information they could use to make their own choices, educators had anointed themselves as the sole mediators of scientific knowledge about AIDS, doling it out in sound bites and slogans that did little to address the underlying reasons why men have sex at all—to say nothing of the reasons, some quite legitimate, they might choose to have unprotected sex.

Educators, who may have had no formal credentials in the relevant areas of public health or behavioral sciences, were accorded a certain prestige in the community. Whatever professional credentials they lacked they simply assumed for themselves in their visible roles. The granting or withholding of “permission” for particular activities by people in positions of authority meant that a high-risk activity like unprotected anal intercourse became “frowned upon,” or stigmatized, in the community. Those who engaged in the forbidden behavior were seen as “sinners,” betrayers of the gay community, shamed into silence.

Of course this meant that when men did have unsafe sex, no one would talk about it for fear of being condemned by these authority figures. As Eric Rofes put it, “It became clear very rapidly which subjects were appropriate to discuss and which ones, under the constraints of safe sex guidelines, had become heretical.”³²³ To admit one had engaged in unprotected anal intercourse—irrespective of the fact that it might well have been a conscious choice because both partners were either HIV-nega-

³²³. Eric Rofes, *Reviving the Tribe: Regenerating Gay Men's Sexuality and Culture in the Ongoing Epidemic* (New York: The Harrington Park Press, 1995), 145.

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tive or positive, so there was no chance of new HIV infection (what is often referred to today as “sero-sorting”)—was certainly seen as heretical, a falling away from the faith. In fact, to prevention educators it was viewed as no less than blasphemy itself against the god of safe sex we had created as our talisman against AIDS.

Prevention educators continued using social marketing techniques to try to make gay men “want” to use condoms. Referring to them as “lifeguards” and calling them by other euphemistic and sexy names, they tried to make safe sex appealing by making it “fashionable”: If you practiced it, you were part of the “in” crowd; if you didn’t, you weren’t. The problem with this approach is that it once again reduced and simplified complex emotions and behavior. As Rofes put it, “Gay men appear as consumers to be pitched specific messages, as if their erotic desires have much in common with consumer urges for Pepsi Cola, a Big Mac, or a Jeep Cherokee.”³²⁴

One of the actual consumer products in which safe sex is literally “packaged” and sold to gay men—even if not everyone buys into it—is gay pornography. Porn videos, like telephone sex, blossomed in popularity in the AIDS epidemic as men sought ways to have sex as safely as possible.

Some activists viewed porn watching as a golden opportunity to influence gay men to have safe sex. Recall that the earliest prevention efforts by the AIDS organizations, created by gay men, were videos of men engaging in safer sex, intended to show by example what it was and that it could be enjoyable. Activists insisted that gay erotica portray only safe sex, that condoms be visible at all times during videotaped anal intercourse. Most filmmakers for the first years of the epidemic

³²⁴. Ibid., 119, 126.

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weren't insisting on condoms because they thought them unerotic. No one insisted on condoms for oral sex—which was surprising in view of the conviction with which so many educators vilified the practice if done without a condom.

Chuck Holmes was the founder in 1971, and then the president of Falcon Studios, at the time of our 1995 interview. San Francisco-based Falcon remains one of the best-known producers and largest distributors of gay male erotica in the country. Holmes served on the boards of several national gay political organizations, including the Human Rights Campaign and the Victory Fund. Not long before our interview Falcon had produced its 100th video. It had an additional seventy titles on its “Jocks” label, more than forty on its “Mustang” label, and its seventh international video was under production in Eastern Europe.

Holmes described Falcon's corporate philosophy as being “proudly, openly gay.” He said that Falcon in the mid-eighties began to use condoms and nonoxynol-based lubricants (the lubricants recommended at the time—before they were found to potentially increase susceptibility to HIV transmission) in its videos, as recommended by prevention educators. He noted, however, that other producers didn't immediately do likewise, and that even in the mid-nineties a condom-free film occasionally would slip into the market. Emphasizing that safe sex had become the norm in gay erotica by that point, Holmes said, “No responsible gay erotica producers would ever make a decision [not to use condoms]. They'd be drummed out of the business because the models wouldn't talk to them, the distributors wouldn't touch it.” He added, however, “Anybody who can get two nickels together can get a high-eight camera and produce gay videos. But the usual distribution channels wouldn't be

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available to them, and a hue and cry would be raised against them.”³²⁵

Boston’s AIDS Action Committee attempted, in the late eighties, to produce a safe sex film featuring porn star Al Parker. Cindy Patton, who worked on the project, notes that the group’s goal for the video wasn’t to “eroticize” safe sex, but rather “to retrieve already and always safe activities,” such as mutual masturbation, licking, and all the other sexual things gay men might do together that seemed to have been lost in the shuffle as everyone focused so singlemindedly on eliminating unprotected anal sex. Ultimately, said Patton, the project was shelved because the group couldn’t agree on what constituted safe sex. But in the process, they learned a valuable lesson.

As Patton put it, “Porn videos are useful if they suggest positive attitudes about gay male sexuality because that helps create and sustain a social environment in which safe sex is practiced because it is viewed as a positive aspect of gay male sexuality.”³²⁶ The group reasoned that gay men would practice safe sex if they were persuaded to view it as something positive rather than as a kind of punishment for being homosexual—as too many men had come to see it.

To reach this point, naturally, discussion would be needed to try to find answers to important questions: Why were men still having unsafe sex? What value did it have for them? Could they learn to value and enjoy a different activity—or, less onerously, continue the ones they already enjoyed but practice them

³²⁵. Charles Holmes, telephone interview with author, 7 April 1995.

³²⁶. Cindy Patton, *Fatal Advice: How Safe Sex Education Went Wrong* (Durham, NC: Duke University Press, 1996), 124–27.

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safely? Unfortunately, this discussion wasn't allowed to happen for several years after it became apparent that some gay men were either not practicing safe sex at all, or were doing so only some of the time. To acknowledge publicly that gay men were flouting supposed community norms meant prevention education wasn't working, and that prevention educators weren't quite as influential as they thought they were.

Some feared that if word about gay men having unsafe sex a decade into the epidemic got out to the public, the long-feared backlash against gay people would happen. AIDS service organizations worried that if politicians found out that prevention wasn't working 100 percent of the time, their funding would be cut. So they did their best to suppress the information, to keep it under wraps in the community. As in the early years of the epidemic, the view was that the community's "dirty laundry" shouldn't be aired in public.

But not everyone agreed this was a good policy. David Ostrow, for one, said, "To me, one of the biggest mistakes in the history of the whole AIDS movement was when, for political reasons, we decided that we would tell the public and the politicians that gay men had stopped having unsafe sex around 1987 or [19]88. I was against it then, and I'm still against it."

It was a political decision to say that gay men stopped having sex without condoms. But, as numerous studies showed, that was never the case anywhere. If the threat of negative pressure was going to be used to motivate gay men to give up their favorite sexual activities, there was bound to be a relapse. "That's the way behavior works," said Ostrow. "When you ask people to give up something, and you don't give them some-

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thing else to replace it that provides the same form of intimacy and pleasure, you're going to have high rates of relapse."³²⁷

The debate over unsafe sex within the gay community reached a fever pitch in 1995. On Easter Sunday, the *New York Times* reported that New York authorities had closed two gay theaters and a sex club. "Places like this facilitate multiple, anonymous sexual contacts, and the risk of transmission is so much greater there," said Doron Gopstein, an attorney for the city who had handled similar cases going back to the 1985 closing of the Mine Shaft. The *Times* noted that the closures may have been little more than a "quick political fix" to the troubling, unanswered question of whether sex in public places was any riskier than sex at home.

The situation wasn't helped by the state sanitary law used to close the establishments, which inaccurately described any oral, anal, or vaginal sex in these places as "high-risk," whether or not a condom was used and regardless of the HIV status of those involved. In the city's convoluted definition, illegal equaled high risk, only further confusing an already difficult issue.

The day after the *Times* report, the *Washington Post* raised its own chagrined voice to note in a front-page article, "A gay men's social club where the lights are low and patrons must leave their clothes in lockers has opened near downtown Washington, reviving a dispute over public health and civil rights in the era of AIDS." The *Post* observed that similar clubs in other cities had become the settings for "proselytizing" AIDS educators "who once condemned such places." The article mentioned—and quickly dispatched—the fact that elsewhere in

³²⁷. David G. Ostrow, MD, interview with author, Chicago, 3 June 1995.

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the city a bathhouse and other establishments catering to those who wanted anonymous sex had remained open throughout the years of the epidemic.

In a follow-up editorial, the *Post* called the new Crew Club “the Washington area’s latest AIDS breeding ground” and “a site that fosters deadly behavior.” Whitman-Walker Clinic director Jim Graham was quoted as saying, “In the midst of an epidemic, I am disappointed this is part of the landscape of this city.”³²⁸

Perhaps if the *Post* had done a more thorough job of reporting the situation, it would have focused on specific acts performed on the premises, before lambasting the Crew Club in sweeping and harsh terms. It also would have noted that the new club was only a few blocks from its own offices. Graham’s own disappointment might have stemmed from the club’s proximity to Whitman-Walker, only a couple of blocks away on the same street. Why hadn’t the newspaper and the clinic been concerned about the city’s other existing sexual establishments? Could it have been that they were simply on the other side of the city, rather than in their own “backyard”? Out of sight, out of mind?

For the rest of the year, the issue of what was being called “permissible sex” dominated the gay press. It seemed that some, including former prominent members of ACT UP/New York, had finally realized that, while the AIDS treatments they advocated certainly were important, there were considerably

³²⁸. Amy Goldstein, “Gay Social Club in D.C. Raises Health Concerns,” *Washington Post* (17 April 1995), 1; Unsigned editorial, “Why Another Bathhouse in DC?” *Washington Post*, (20 April 1995).

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more gay men at risk for contracting HIV than there were those already infected with it.

Activists had never given prevention the same priority as treatment. Suddenly, and with both the zealotry and “religion” of new converts, the self-styled “prevention activists” in 1995 tried to rally the community to pay attention to what they asserted was a huge new upswing in unsafe sex. Some had personally observed unprotected sex in the clubs, and then apparently looked for data to support their assumption that gay men everywhere had “relapsed.” With arguments harkening back to the bathhouse controversies of the early eighties, some went so far as to call upon public health and legal authorities to police, or even close down, sexual establishments.

In New York small groups of prevention activists formed in 1995 in response to reports of unsafe activity in the clubs, each with its own “solution” to the “problem” of unsafe sex. Two of the groups, Community AIDS Prevention Activists (CAPA), and the AIDS Prevention Action League (APAL), viewed AIDS prevention as an issue to be solved within the gay community itself. The two groups were founded by HIV-positive men who feared that a quick fix, like closing sex clubs and bathhouses, would simply drive unsafe sex back to the parks and piers—where, incidentally, as I have personally observed, it has never ceased or abated in spite of the availability of indoor spaces and Internet chat rooms catering to men seeking it. Carlos Cordero, founder of CAPA, said, “If you want behavioral change, then you have to give people support at every level, not condemnation or vilification. There’s such a hunger to talk about stuff, but people really need to feel safe to talk.”³²⁹ Stephen Gendin, APAL’s founder, wrote an open letter to the

³²⁹. Sara Miles, “And the Bathhouse Plays On,” *Out* (July/August 1995).

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community in which he said, “Do not demonize gay men because of where we choose to have sex. Do not take away our ability to make choices for ourselves. Do not characterize gay men as victims who have no ability to control ourselves. Do not polarize the discussion before it even begins.”³³⁰

Unfortunately, the reasonable voices of these two men were virtually drowned by the flood of outraged op-ed pieces and articles of the media-savvy handful of members of a third group called Gay and Lesbian HIV Prevention Activists (GALHPA). Led by gay journalists Duncan Osborne, Gabriel Rotello, and Michelangelo Signorile—“along with a handful of other skilled propagandists,” as *POZ* magazine described them³³¹—the group demanded, in the pages of the city’s mainstream newspapers, that the city close down establishments that allowed their patrons to have unsafe sex. Acknowledging that they had patronized such establishments themselves—presumably to have sex like the other men there—GALHPA activists didn’t see a contradiction between their own activity and their call for closure by a city government that considered any sex in such places to be illegal and, therefore, “high-risk.” *Out* magazine quoted Gabriel Rotello as saying, “HIV transmission must stop. And a moderate restriction in civil liberties, if that’s going to make the difference between salvation and catastrophe, then that’s something we have to accept.”³³²

Such views were roundly condemned by many other gay men, weary of being viewed as criminals merely because of

³³⁰. Ibid.

³³¹. David France, “Second Wave, Second Thoughts,” *POZ* (June/July 1995).

³³². Miles, “And the Bathhouse Plays On.”

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their sexual orientation. Ben Stilip, director of communications for New York's Lesbian and Gay Community Services Center, said, "Why would we invite the very institutions that in so many ways ignore and hurt and neglect us to police our lives? It's like inviting Mata Hari over to baby-sit your kids."³³³ The single-minded focus of Rotello and his fellow GALHPA members on sexual establishments ignored what prevention researchers had been saying for years: Most of the unsafe sex transmitting HIV takes place in the privacy of the bedroom, not in public places. In his regular *Out* column, GALHPA member Signorile quoted Columbia University AIDS researcher Martina Morris as saying, "Public sex is not the problem. Unsafe sex is the problem."³³⁴

Bob Warfel, a professional health educator in Washington, DC, responded to the flap over the city's Crew Club in the kind of thoughtful and reasoned fashion that eluded New York's GALHPA and, it seemed, most everyone else. In a letter to the editor published in the *Washington Blade*, Warfel wrote, "There is no reasonable—or realistic—argument for prohibition. And there shouldn't be as long as the majority of people are self-aware and capable of making personal decisions or choices. For those who cannot—because they are impaired by alcohol, or drugs, or low self-esteem—there are much more effective things our community could do for our brothers than shutting down a club. Like, perhaps, talking about why so many find anonymous sex—or getting trashed, or getting stoned, or

³³³. Ibid.

³³⁴. Michelangelo Signorile, "All Unsafe Sex Isn't Created Equal," *Out* (October 1995), 30–33, 138.

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putting each other down—so appealing or necessary in the first place.”³³⁵

A discussion of self-esteem and mental health issues during the first-ever national summit on HIV prevention, sponsored by the Gay and Lesbian Medical Association and held in Dallas in July 1994, revealed the paucity of attention these issues had received in the community’s prevention efforts. In a workshop led by Tom Moon, issues of isolation, alienation, a sense of not belonging, loss, and absence of family were among the reasons cited for many gay men’s ongoing risky behavior.

The group concluded that to be effective, prevention education should address issues of wellness, self-esteem, self-love, and the affirmation of love. One major obstacle to achieving these goals, said Moon, is society’s treatment of gay men as outlaws. As he put it, “Until we have our civil rights, self-esteem is going to be very difficult to attain.” In the meantime, the group urged community advocates to speak publicly about gay mental health issues “without apology or fear of backlash or airing ‘dirty laundry.’”³³⁶

One speaker at the Dallas summit who generated considerable debate was Berkeley, California, psychologist Walt Odets. With his sharp criticism of what he viewed as outmoded prevention efforts, Odets became a lightning rod for prevention

³³⁵. Bob Warfel, “The Bottom Line” (Readers Forum), *Washington Blade* (26 May 1995), 43.

³³⁶. Gay and Lesbian Medical Association, *The Silent Crisis: Ongoing HIV Infections Among Gay Men, Bisexuals and Lesbians at Risk*. Report of the GLMA/AAPHR Summit on HIV Prevention for Gay Men, Bisexuals and Lesbians at Risk, Dallas, Texas, 15–17 July 1994.

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educators loath to let go of the slogans and strategies they had used in one form or another since the early years of the epidemic.

Of the community's efforts to "hide" unsafe sex, Odets in 1995 told me, "This apologist approach that says we should keep our problems under our hat because people won't like us, that we have to fight for our rights to be human, to have foibles and complexity—it hasn't accomplished anything. We're never going to get anything by being good; we never have, they're not interested in us. We're not going to make them less interested by revealing that we're human beings."

Odets believed that the incidence of unprotected anal sex among gay men was much higher than reported in the literature, and certainly higher than gay men report to one another, because they, like almost everyone, underreport all stigmatized behaviors. And, as he stressed, unprotected anal sex, regardless of the partners' HIV status, had indeed become highly stigmatized. "A man who seroconverts now has a lot of explaining to do," said Odets. "He explains it by saying 'I just suck guys off; I never had anal sex in my life.'"

As he does frequently in his writing and talks, Odets offered an illustrative anecdote from his mostly gay psychotherapy practice. A couple he was seeing in therapy had an arrangement that allowed each man to have sex with others outside the relationship as long as it was safe. One of the men got infected with HIV, but denied having had unprotected sex. After six months of individual therapy with the HIV-positive man after the couple broke up over the issue, he finally admitted the truth. He told Odets, "Dan and I had a fight one night and I went to the baths and I let a guy fuck me without a condom." To show how much shame this man felt about his behavior—instilled by prevention educators—Odets contrasted it with another experience

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in the man's past. "One of the first things he told me in therapy," said Odets, is that he'd grown up fucking the family collie! He didn't mind telling me *that*. He spent his whole childhood fucking the collie, but he couldn't tell me about anal sex."

Acknowledging and discussing unsafe sex are even harder when people perceived as community leaders harshly condemn such behavior and go so far as to call for draconian measures to suppress it. As Odets put it, "A lot of people don't trust their own impulses and want external control—like the bathhouse thing in New York. It seems to me to be a lot of anxious people who want external controls to deal with their own impulses about things."³³⁷

As prevention researchers explored the workings of the gay male psyche in the second decade of the epidemic, trying to learn why some men would have unprotected sex despite its potential risks, they also began to look at what we might call situational co-factors that contribute to unsafe sex. Topping the list of circumstantial enablers is alcohol and drug use. "Substance abuse is one of the principal risk factors for getting infected," said Tom Coates, a psychologist and at the time of our 1995 interview director of the AIDS Research Institute at the University of California–San Francisco. "We have terrible epidemics of substance abuse in the gay community—a lot more than in the general heterosexual population—alcoholism, cocaine, and amphetamine use." He noted that the central role of bars in the social lives of many gay people fosters the overconsumption of alcohol and the accompanying inability to make healthful choices.³³⁸

³³⁷. Walter Odets, interview with author, Chicago, 2 June 1995.

³³⁸. Thomas J. Coates, interview with author, Washington, DC, 16 May 1995.

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In early 1995, psychiatrist Bob Cabaj had recently left his position as director of the substance abuse and HIV program at San Francisco General Hospital, and was the president of the Gay and Lesbian Medical Association. A noted expert on issues around substance abuse in the gay community, Cabaj told me, “I have seen tremendous numbers of gay men who abuse substances.”

Cabaj described a pattern of drug use among a fairly large number of gay men in San Francisco and elsewhere along the West Coast that, he said, even shocked him. “I did not see a single gay male patient with HIV at the General for the three years I was there who was not also an IV-injecting speed user.” By the mid-nineties, methamphetamine, commonly known as “crystal meth,” speed or “Tina,” had become the drug of choice among many gay clubgoers from Los Angeles up to Seattle. “It’s so addicting,” Cabaj explained. “Your tolerance goes up so high that you don’t get anything after a while from snorting, so you have to start injecting.”

Were gay men who injected the drug sharing needles? I asked. “Yes,” he answered. “Of course everyone starts out with the best intentions. But once you’re high from the first shot, you’re not going to worry about whether the sex you have is protected or not.” And men on “crystal” tend to have a lot of sex because one of the drug’s effects is to make one “hypersexual,” capable of multiple episodes over the course of a strung-out, sleepless, sometimes days-long “trip.”

This information was astonishing given the presumably high level of knowledge among middle-class gay men, particularly in San Francisco, about the most basic ways to protect themselves against HIV infection—foremost among them, not to share needles. I pursued the questioning further. “Does their

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sharing needles have something to do with the fact that they don't see themselves as junkies because they're not poor, don't have ragged clothes, or dark skin?" Cabaj answered, "Exactly."³³⁹

Recalling Reggie Williams' description of the "double-edged sword" that gay men of color face—not fully at home in either the white gay community because of their race, or in their racial or ethnic community because of their sexual orientation—it wasn't surprising to learn that Black gay men were especially susceptible to substance abuse and its attendant HIV-related risks.

But even prevention efforts targeting gay men of color typically viewed them as either substance abusers or homosexual, as though the two are mutually exclusive identities rather than behaviors that often go hand-in-hand. In 1995, 35 percent of the clients at San Francisco's Eighteenth Street Services, a highly regarded substance abuse treatment program in the heart of the Castro district, were Black gay or bisexual men. The agency's outreach director, Bert Bloom, said that for Black gay men, like white gay men—and people in general—"If everybody is telling you that you are worthless and you feel like shit, why not get high?"³⁴⁰

That at least will help to keep you from dealing with yourself, even if it also prevents you from taking precautions against HIV. As Bob Cabaj put it, "Unless you can generate a sense of confidence or a sense that you're okay with who you are, you don't

³³⁹. Robert Paul Cabaj, MD, interview with author, San Francisco, 4 February 1995.

³⁴⁰. Sidney Brinkley, "Letter from San Francisco: Getting the Message Out," *Washington Blade* (7 April 1995), 14.

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do much to protect yourself in life.” For Cabaj, coming to terms with being gay is the starting point for self-esteem—and, by extension, for HIV prevention. “Drugs and alcohol have a tremendous impact in helping us to dissociate and deny,” he said. “So some people can have gay sex after they get drunk. They don’t think about it, but substance abuse is woven very tightly into the gay community in promoting disconnection and denial.”³⁴¹

Bars and nightclubs are typically major ports of entry for young gay men coming out into the community. From the beginning of their gay “career,” many young gay men are exposed to situations that aren’t necessarily the most conducive to their health and well-being.

Unfortunately it’s not terribly surprising that there are frequent lapses in safe sex among many younger gay men, often under the influence of alcohol or drugs, and at least partly because they haven’t had firsthand experience of seeing their friends get sick and die. A 1996 report by the Office of National AIDS Policy indicated that of the then-estimated forty thousand to eighty thousand Americans infected with HIV each year—between 110 and 220 a day—from twenty-seven to fifty-four of the daily infections were among young people under the age of twenty.³⁴²

After an interview I had with Patsy Fleming, then director of the Office of National AIDS Policy, Fleming called me because, she said, she wanted to make a couple of points about young gay men. The mother of a young gay man herself, Fleming soft-

³⁴¹. Cabaj interview.

³⁴². Office of National AIDS Policy. *Youth & HIV/AIDS: An American Agenda* (Washington, DC: Office of National AIDS Policy, March 1996).

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ly (and, I thought, sadly) told me that she had met young men who actually wanted to become infected with HIV. “I run into young gay people,” she said, “who say they are negative, but go into an AIDS organization and say they are positive so they will get attention.”³⁴³

The rising rate of new infection among young gay men certainly got attention. A 1993 survey by the San Francisco Health Commission found that nearly 12 percent of twenty- to twenty-two-year-old gay men in the city were already HIV-positive, as were 4 percent of seventeen- to nineteen-year-olds. “If those figures are not reversed,” noted the *Advocate*, “the current population of young urban gay men”—what the magazine already was calling the “lost generation”—“will have as high an infection rate by the time they reach their mid-thirties as middle-aged gay men are thought to have already—close to 50 percent.”³⁴⁴

Gay youth remained at particularly high risk for HIV infection, and not merely because they tend, like all adolescents, to engage in risky behavior. Pediatrician Gary Remafedi, a nationally known expert on gay adolescents at the University of Minnesota, told me that his research on young gay males has found certain predictors of risk that make them especially vulnerable. These include substance abuse; being in a steady relationships (they “trust that their partner is not going to do anything to hurt them,” said Remafedi); academic under-achievement; having a lot of gay friends, which provides more opportunities to meet others and engage in unsafe sex; and, perhaps

³⁴³. Patricia Fleming, telephone conversation with author, 22 March 1995.

³⁴⁴. Chris Bull and John Gallagher, “The Lost Generation,” *The Advocate* (31 May 1994), 36–40.

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most alarming, he said, “risky behavior is associated with the belief that they are likely to get HIV.”

With a sense that HIV infection is inevitable, these young people give up on safe sex before they’ve even had the chance to discover behavior that can be both healthy and satisfying. Remafedi explained, “Young people who are well-instructed have grown up to think of safe sex as sex, period. On the other hand, when young people come out they hear from adults, ‘You’re going to get AIDS and die.’ Young people who have to deal with the possibility that they have been exposed are often fearful to find out whether they have HIV because it fulfills the parent’s prophecy.”³⁴⁵

A 1995 study of 149 young gay men in New York, including ten who were HIV-positive, found that those who had partners over the age of twenty-five tended most often to have unprotected anal sex, the highest possible risk behavior. They were described as “the leading edge of infection” for their age group. “It is clear that young gay men are now standing on the brink of a second wave of the AIDS epidemic in their community,” the Columbia researchers concluded.³⁴⁶

A companion study reported that in 1990–91, 62 of the 149 young men in the study—nearly half—had engaged in unprotected receptive anal intercourse, mainly at home. Compared to the men who didn’t do it, more men who engaged in receptive

³⁴⁵. Gary Remafedi, MD, telephone interview with author, 14 July 1995.

³⁴⁶. Martina Morris, Jane Zavisca, Laura Dean, “Social and Sexual Networks: Their Role in the Spread of HIV/AIDS Among Young Gay Men,” *AIDS Prevention and Education* 7 (1995): 24–35.

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anal sex knew the HIV status of their partner. (In a significant oversight, the report doesn't note whether or not the men knew beforehand if their insertive partners were HIV-negative or positive.)

The study drew a very disturbing conclusion reminiscent of the sometimes-rancorous arguments in the gay community over issues like sex clubs and bathhouses. It found that for the young gay men studied, higher levels of risk-taking correlated to their involvement in the gay community. This would seem counterintuitive to the prevention educators and activists who claimed the gay community had become a "safe sex culture."

But the researchers noted, "This suggests that a strong community consensus may have adverse effects by forming the impression that risky behavior is extremely rare, and by creating taboos that inhibit open discussion of sexual behavior."³⁴⁷ What's more, for young gay men coming out in the urban ghettos where there are high rates of HIV infection, being HIV-positive can too easily seem not only inevitable but "normal." Walt Odets said, "In this social and psychological climate, we are now also seeing younger gay men who are often unable to make any distinction at all between being gay and being at risk for, or actually contracting, HIV."³⁴⁸

Is this what gay liberation and the community's awesome response to AIDS had come down to? A perverse state of af-

³⁴⁷. Ilan H. Meyer and Laura Dean. "Patterns of Sexual Behavior and Risk Taking Among Young New York City Gay Men," *AIDS Prevention and Education* 7 (1995): 13–23.

³⁴⁸. Walter Odets, *In the Shadow of the Epidemic: Being HIV-Negative in the Age of AIDS* (Durham, NC: Duke University Press, 1995), 102.

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fairs in which the words “gay” and “plague” had become synonymous? As gay men in the late nineties continued to become infected with HIV and die of AIDS in staggering numbers, the community still struggled to address the troubling issue of unsafe sex, too often in harsh, condemnatory terms. Gay men who had risky sex felt they couldn’t bring up the subject with gay friends because no one was willing to risk censure by talking about it. So they didn’t talk about it. Yet they continued to do it, fearful and furtive lest their friends find out and upbraid them for being so “stupid.” They felt they couldn’t talk with AIDS educators about it, either, because that risked being criticized for violating a supposed “community norm” which said, in effect, unprotected sex is “abnormal.” So they accepted the risk of HIV infection as simply a kind of occupational hazard in the business of being gay.

Were they fools? They were hardly ignorant. Did they have a death wish? A deep-seated desire to end a lifetime of pain caused by being considered sick, criminal, and second-class? “They don’t,” said Tom Coates. “They have a love wish.”³⁴⁹ Used to rejection and condemnation simply for having a different sexual orientation than that of most people, gay men want to be loved. Like virtually everyone with a beating and breakable heart, gay men can be, and often are, fools for love. But was heaping yet more scorn on them the way to make them want to protect themselves and one another from HIV? Or was there a better solution in creating prevention efforts that would begin by making gay men feel so loved, so cared for, and so respected that they would treat themselves and each other the same way? The answer seemed obvious in light of the failure of the former approach. Of course the latter requires a great deal

³⁴⁹. Cynthia Laird, “UCSF AIDS Fighters Talk About Their Work,” *Bay Area Reporter* (19 September 1996), 26.

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of work—and a considerable amount of heart. Surely the lives of gay men are worth the effort.

And surely if anyone ever doubts the ability of gay men to effect change, all they have to do is look at the way gay men with AIDS effected unprecedented changes in American medical research and in how medical consumers are treated. Insisting that their voices be heard and their needs considered, they challenged the system to become better than itself. The rage of an oppressed, distressed people, aimed at appropriate “targets” and not at one another, yielding to reason once they were listened to, could change the world. That is precisely what gay men with AIDS did.

PART 5

THE MAKING OF SOLDIERS

*To skies that knit their heartstrings right,
To fields that bred them brave,
The saviours come not home to-night:
Themselves they could not save.*

A.E. HOUSMAN, *A SHROPSHIRE LAD* (1887)

Gay men “came out” as having AIDS the way they had come out as being gay. Their years spent “convalescing” had given these men a confidence that their lives had value. By again challenging the medical establishment—as they’d challenged the American Psychiatric Association a decade earlier—gay people subverted the power of those who masked their antigay policies in the guise of “science.” Activists in the eighties presaged the national debate over health care during the Clinton and Obama years, arguing that, with a new disease like AIDS, the testing of experimental treatments was tantamount to health care and so should not be denied to anyone. After activists gained access to the highest levels of the nation’s medical research institutions, some of them strangely started to sound like the very scientists they had condemned. But even in compromising the gay community’s important critique of medical research and health care, these amateur scientists emulated their courageous predecessors in their desire to survive. That was the point, after all.

SIXTEEN

When he wasn't in the nurse's uniform he wore for his job, Bobbi Campbell often slipped into the habit of his alter ego, Sister Florence Nightmare, one of San Francisco's famous Sisters of Perpetual Indulgence. After he was diagnosed with Kaposi's sarcoma in September 1981, Campbell's willingness to stand out from the crowd led him to stand up and be counted as the first person with AIDS ever to go public about his disease. Proclaiming himself the "KS Poster Boy," Campbell in early 1982 began to write a regular column for the San Francisco *Sentinel*, in which he explained what he was experiencing and offered suggestions to others. Besides the KS lesions on his foot, Campbell sported a button that captured in one word the singular objective he and everyone else ever diagnosed with AIDS hoped and worked for. "Survive," it said.

In February 1982, Marcus Conant suggested that Dan Turner get together with Campbell to share experiences, after Turner was diagnosed with KS. Their meeting at Turner's house planted the seed for what in a few years would be a nationwide movement of people with AIDS committed to their own and one another's survival. Conant and his colleague Paul Volberding invited Turner and Campbell to attend what turned out to be the founding meeting of the K.S./AIDS Foundation. Their early involvement with the foundation showed them firsthand the vital roles that people with AIDS could play in AIDS service organizations as advisers, and often as actual service providers themselves, if they were well enough. Together with a few other people, the two men cofounded a group that became People With AIDS—San Francisco, the first organization anywhere of and for people with AIDS.

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Across the continent, Michael Callen and Richard Berkowitz followed up their November 1982 article “We Know Who We Are” by organizing a support group called, simply, Gay Men With AIDS. The two met other people with AIDS at the first peer-led emotional support group in New York for those diagnosed with the disease, offered by Beth Israel Medical Center psychiatrist Stuart Nichols. Callen borrowed a page from Alcoholics Anonymous and other twelve-step support groups in defining the goal of Gay Men With AIDS as supporting each other by “sharing our personal experiences, strength, and our hope.”

Some people with AIDS in New York had heard of Bobbi Campbell and were torn between thinking him either courageous or foolish for his willingness to publicly identify himself as a gay man with AIDS. Word reached New York in the spring of 1983 that Campbell was urging the fledgling AIDS service organizations in various cities to pay the expenses of gay men with AIDS to attend the upcoming Second National AIDS Forum, in Denver, to be held in conjunction with the annual lesbian and gay health conference.

Michael Callen recalled, “The idea struck like a bolt of lightning. Until then, it simply hadn’t occurred to those of us in New York who were diagnosed that we could be anything more than passive recipients of the genuine care and concern of those who hadn’t (yet) been diagnosed.” But gay San Franciscans were long used to taking an active role in the life of their city, and naturally expected the city to commit its political and financial resources to help save the lives of its residents who had AIDS.

Calling attention to the epidemic and commemorating those who already had been lost, gay men with AIDS carried a ban-

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ner during the first AIDS Candlelight March, in San Francisco, on May 2, 1983. “Fighting For Our Lives,” it said. The following month, Bobbi Campbell and Dan Turner took the banner to the AIDS forum in Denver, where its message of hopeful determination was adopted as the motto for people with AIDS.

A dozen people with AIDS met together in a hospitality suite during the conference to talk about how they might organize themselves. Bobbi Campbell took charge of the room, articulating plans for a coalition of political groups in all the cities with large AIDS populations, and proposing that the local groups join one another in forming a national group.

Campbell also conveyed the wish of his fellow San Franciscan, Mark Feldman, who had succumbed to AIDS just before the conference, that terms like “patient” and “victim” should be rejected because they were disempowering. After some skepticism about the significance of what is in a name, the New York contingent joined the group from California to insist that those with the disease be known simply as “people with AIDS,” or “PWAs.”

The PWAs who met in Denver realized they shared the same frustration with not being listened to by health care providers—or even, too often, by those who were providing services to them in the new AIDS service organizations. They drafted a manifesto known as the “Denver Principles,” a series of rights and recommendations for health care providers, AIDS service organizations, and people with AIDS themselves. The principles echoed a 1976 manifesto of the San Francisco Gay Democratic Club, formed by Harvey Milk (later renamed in his honor after his assassination in 1978), which said, “No deci-

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sions which affect our lives should be made without the gay voice being heard.”³⁵⁰

The Denver Principles became the charter of the movement for PWA self-empowerment. Among them was the recommendation that people with AIDS “be involved at every level” of AIDS service organizations, and that they retain the right “to full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment, and to make informed decisions about their lives.”

Above all, the group was determined to arm themselves with as much information—at times the only ammunition they had, and always a key source of firepower in this war—as they could lay their hands on, girding for the medical and political battles that lay ahead.

These people with AIDS were not a passive lot, to put it mildly. As middle-class white American men, they felt a strong sense of entitlement to support and health care services that all middle-class people in this country take for granted. As they put it in the preamble of the Denver Principles, “We condemn attempts to label us as ‘victims,’ a term that implies defeat, and we are only occasionally ‘patients,’ a term that implies passivity, helplessness, and dependence upon the care of others. We are

³⁵⁰. Randy Shilts, *The Mayor of Castro Street: The Life and Times of Harvey Milk* (New York: St. Martin’s Press, 1982), 150.

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‘People With AIDS.’”³⁵¹ PWAs hoped that by seizing the word “victim,” challenging its meaning, even eschewing it altogether, their roles in the epidemic might be changed from being mere casualties to active participants in the fight against it—the fight of their lives, for their lives.

After the Denver meeting, Bobbi Campbell flew with Callen, Berkowitz, and former newspaper reporter Arthur Felson, from Denver to New York, to plan a national group. In New York, an ad in local gay papers led to the formation of PWA-New York, a political organization for people with AIDS that foundered before long because of internal dissent, the deaths of many of its founders, and an inhospitable environment.

From its ashes arose the PWA Coalition. Its monthly newsletter *PWA Coalition Newslite*, and a book it produced called *Surviving and Thriving with AIDS: Hints for the Newly Diagnosed*, became valuable sources of information for thousands of people with AIDS in New York, across the country, and throughout the world.

On the other coast, PWA–San Francisco also thrived. Bobby Reynolds, a gay man diagnosed with AIDS in June 1982, was on the first executive committee of PWA–San Francisco. Asked in an early interview what he thought about being public with his AIDS diagnosis in view of the stereotypes about people with AIDS, Reynolds said, “I felt that they were putting me on a file card and just sticking me away somewhere. So I made the decision to start speaking out, and I became known as Bobby

³⁵¹. Michael Callen and Dan Turner, “A History of the People with AIDS Self-Empowerment Movement.” In Michael Shernoff, William A. Scott, eds., *The Sourcebook on Lesbian/Gay Health Care* (Washington, DC: National Lesbian/Gay Health Foundation, 1988), 187–192.

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Reynolds, the person with AIDS, and consequently they're going to know that I'm Bobby Reynolds, a gay man who has AIDS."

Reynolds likened the experience to "coming out" as homosexual. He said, "We've talked in group [therapy] about how coming out with AIDS is similar to coming out of the closet as a gay person: a lot of questioning, a lot of trying to find your identity, who am I as a gay man, who am I as a gay man with AIDS? It's like crawling—starting out in diapers and then crawling, then standing up, then taking your first step, and it's very similar, I think, to what people go through coming out."³⁵²

Shortly after the first reports of AIDS in the press in 1981, Larry Mass asked Donald Krintzman in a *New York Native* interview about being a "cancer patient." Before AIDS had a name, someone with Kaposi's sarcoma—one of the most common and visible AIDS-defining infections in those years—was simply called a cancer patient. How, asked Mass, did this new identity fit with his other identities—including gay, male, American, Jewish, and New Yorker. Krintzman, the former lover of GMHC cofounder Paul Rapoport (who himself died of AIDS) and the first person with AIDS ever interviewed in the press, answered, "I think my new identity as a cancer patient is less powerful than my new identity as a man who may be facing death." In fact, Krintzman was only three months away from his death in November 1981.³⁵³

³⁵². Lon G. Nungesser, *Epidemic of Courage: Facing AIDS in America* (New York: St. Martin's Press, 1986), 119.

³⁵³. Lawrence D. Mass, MD, *Dialogues of the Sexual Revolution*, vol. 1 (New York: The Haworth Press, 1990), 119.

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Many lives would have ended sooner had it not been for two gay men in San Francisco, neither of them infected with HIV, who understood the importance of information and self-determination to the well-being of people with HIV infection and AIDS. Martin Delaney was suffering from chronic hepatitis when he moved to California before the start of the AIDS epidemic. A treatment research program at Stanford University opened his eyes to the way people with life-threatening illness are treated in the medical system.

Delaney told me in 1995, “I was one who lucked out. The drugs worked.” He referred to the “dark side” of research to describe the side effects of the drugs, and the fact that treatment didn’t work for everyone. For those not even involved in the study, the effectiveness of treatment was a moot point because for them there simply was no treatment. “It became clear,” said Delaney, “that the same issue was involved with PWAs. Once scientists identified the cause, and knew that there are things out there that may be helpful to you, they said, ‘You can’t have them. We in our largesse in the government will decide.’” He added, “This is the Big Brother way they’ve dealt with other life-threatening illnesses.”

In 1985 Delaney founded Project Inform, to study the benefits and drawbacks of PWAs’ taking treatment issues into their own hands. The project, originally an academic study expected only to last six months—observing its twenty-fifth anniversary as I write—turned up other issues that were clearly important to address in defining the scope of self-empowerment in the area of medical treatment: How did people make decisions? How would they know the way to use medications? Said Delaney, “Doctors had no answers, the government had no answers except to say wait, we’ll figure it out for you.” Project Inform’s message of “hope and empowerment through information” was appealing to people with AIDS whose combination of fear and

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fearlessness drove them sometimes to take desperate measures in their efforts to survive.

In providing information through its hotline and newsletter, *PI Perspective*, Project Inform helped to create what would become a unique relationship between many people with AIDS and their health care providers—“changing the doctor-patient relationship from ‘priest-suppliant’ to ‘co-conspirator,’” as Delaney put it.³⁵⁴

I was struck by the sheer size of John James, a tall man whose Levi’s measured forty-two by thirty-eight, when he answered the front door of his house in the Castro district. The house was well known as the site, at one time or another, of a number of gay and AIDS organizations, ranging from the National Task Force on AIDS Prevention to the Gay and Lesbian Medical Association. I had often heard that James held a concern for the gay community in proportion to his stature. In 1986, James began writing a weekly column for a local gay paper on experimental AIDS treatments, which evolved into *AIDS Treatment News*. James continues to publish the journal online out of his more recent home in Philadelphia.

In the mid-eighties, said James, “Treatment information was unrespectable because the view then was that everybody with AIDS dies and service organizations felt they weren’t supposed to be involved between doctor and patient.”³⁵⁵ James, however,

³⁵⁴. Martin Delaney, telephone interview with author, 7 February 1995.

³⁵⁵. John James, interview with author, San Francisco, 4 February 1995; Sidney Brinkley, “Helping People Save Their Lives,” *Washington Blade* (3 June 1994), 18.

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understood that information was essential even in the absence of effective treatment.

Commonly during the AIDS epidemic patients—particularly gay men, because AIDS treatment information was frequently discussed in the gay press and among friends—have been better informed about emerging treatments than their physicians, especially if they are in a part of the country with a low incidence of HIV. If learning about AIDS seemed optional for some doctors, for the gay men they treated it was a matter of life and death.

Mervyn Silverman, director of San Francisco's health department at the beginning of the epidemic, said that not only was AIDS a different kind of disease in medical terms, but gay AIDS patients were different from the typical patients who pass through a doctor's office or hospital. "The average gay man knows more about HIV/AIDS than the average physician," Silverman told me. "This can be daunting for physicians to deal with. It speaks to the need for a partnership between the doctor and patient."

Silverman said that gay PWAs, besides being well informed and actively involved in their own care, also benefited from their connections to the gay community. "This was the first time in history that a community of individuals, linked by various media and socially, were afflicted, so the response was a collective response," he said. Because gay physicians were both members of the community and typically the first to treat AIDS in their gay patients, Silverman noted, "The doctor looked at himself as a potential patient, so was more willing to work with the patient."³⁵⁶

³⁵⁶. Mervyn Silverman, MD, telephone interview with author, 15 February 1995.

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In some cases, the doctor himself actually became a patient. Atlanta physician Stosh Ostrow has a thriving HIV practice—and is himself living with HIV. His own experience led Ostrow to prefer working with patients who participate in their own health care decisions. Until he began to treat people with HIV, though, Ostrow said these “activist” patients were rare. “I quit medicine on a couple of occasions,” he said, “because I couldn’t make people well. It took me a long time to figure out that my job is to present people with opportunities and allow them to make choices.”

Ostrow noted that for gay men with HIV, the beginning point of taking an active role in their treatment—as it is in prevention—has been self-acceptance. As he put it, “How can you be comfortable dealing with your disease when you’re not even comfortable about who you are?”³⁵⁷

Dennis Altman has pointed out that one uniquely important benefit of people with AIDS taking an active role in their own care is that it provides medical science with firsthand information about the disease from those who actually have it. This adds a level of information about the disease usually unavailable to science and medicine.

Gay men have been particularly successful at contributing to the understanding of HIV because of their willingness to put themselves forward and speak forthrightly about their experience. “I have spent time with some remarkable men with AIDS,” writes Altman, “and have listened to their presentations at conferences, and I am struck by their capacity to understand the

³⁵⁷. Stosh Ostrow, MD, telephone interview with author, 23 September 1995.

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social and political implications of their illness and to communicate this to others.”³⁵⁸

Even as gay people with AIDS helped educate doctors and scientists about HIV, they continued to share information with one another through PWA coalitions, in the gay press, and in town meetings. When the Food and Drug Administration (FDA) in March 1987 approved AZT—azidothymidine—“the world of clinical research was turned upside down,” as the National Academy of Sciences put it.³⁵⁹

The first drug ever approved by the government to treat HIV brought an exciting burst of sunshine into the gloaming world of people with AIDS desperate for any kind of relief from the mounting physical ravages of the virus. But the excitement was immediately tempered by the \$10,000 annual price tag that Burroughs Wellcome, the manufacturer of AZT, said was necessary to recoup its research costs. Six years into the epidemic, the first seemingly effective drug ever approved to treat HIV was going to be out of reach of most of the people who needed it.

As they had before, gay people with HIV and AIDS, together with their supporters, took action. ACT UP (AIDS Coalition to Unleash Power) formed in New York to insist on access to experimental treatments. In San Francisco, thousands of people gathered in the Castro area to kick off a thirty-mile, two-day

³⁵⁸. Dennis Altman, *AIDS in the Mind of America* (New York: Anchor Press/Doubleday, 1986), 96.

³⁵⁹. Albert R. Jonsen and Jeff Stryker, eds., *The Social Impact of AIDS in the United States* (Washington, DC: National Academy Press, 1993), 91.

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march to Burroughs Wellcome's offices in a bid to draw attention to the drug's high price.

From the protests emerged an organized process to circumvent the government's lethargic drug development process by procuring drugs approved in countries outside the US and making them available to people with AIDS who were willing to take them. Under an FDA regulation that allows individuals with life-threatening diseases to import for personal use drugs approved elsewhere, "buyers' clubs" were formed to buy such drugs in bulk for distribution among people with AIDS throughout the country.

Michael Callen and Tom Hannan, another man with AIDS, announced the launch of a buyers' club, the PWA Health Group, in New York in April 1987. The two had formed a partnership to import a food substance manufactured in Israel from egg whites, called AL-721, believed to have some effect against HIV, based on test tube studies.

Callen said, "If a substance cannot hurt and may help, we will make every effort to see that those PWAs who desire to obtain such a substance may do so."³⁶⁰ Desperate times called for desperate measures. For Callen and other people with AIDS, the issue was a matter of self-determination: If they were willing to try an experimental treatment, why should they be denied the opportunity to do so by a paternalistic government's drug regulation system?

Speaking on behalf of people with AIDS and everyone else who was puzzled by the slow pace of treatment research, Callen said, "Why do PWAs themselves have to take time and energy from their own individual struggles for survival to do the

³⁶⁰. Michael Callen, Remarks, 24 April 1987.

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job that others are supposed to be doing?” Callen said he hoped not to be in the “business” of importing drugs for long.³⁶¹

AL-721 turned out to be essentially useless, like so many other substances and drugs lauded and then dismissed as the hoped-for cure. In 1988, a Japanese drug called dextran sulfate was the rage. In 1989, the PWA Health Group imported two drugs from England that would indeed prove effective, as well as receive the FDA’s imprimatur as treatments for AIDS-related infections. Fluconazole was brought in after appearing to be useful in treating cryptococcal meningitis, an inflammation of the lining of the brain affecting 10 to 15 percent of AIDS patients.

Aerosol pentamidine, used to prevent *pneumocystis* pneumonia, was already available in the US but was very expensive. The drug typically cost \$125 to \$175 per dose in the States, but the PWA Health Group imported it and made it available for only \$40. Naturally the American manufacturer didn’t appreciate the profits it lost because of people with AIDS who refused to be ripped off and found a way to avoid paying the inflated domestic price of the drug.

As sales of AL-721 reached the \$1 million mark in its first year, the PWA Health Group knew that it needed someone to organize and run its underground medication distribution operation. Derek Hodel was volunteering as a crisis intervention worker at GMHC in the late eighties when he realized that his volunteer work was more interesting and important to him than his day job. After seeking a job in what he called the “AIDS business,” the PWA Health Group hired Hodel to be its first paid executive director. Hodel, who led the group from 1988 to 1992, said the PWA Health Group always saw its mission as going

³⁶¹. Ibid.

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beyond simply importing drugs for people with AIDS. “They tried real hard to be thoughtful and to take actions that would have a larger policy implication, rather than simply providing drugs,” he told me.

Sally Cooper, Hodel’s successor as director of the PWA Health Group, explained that the group had always pursued a “twin mission” of giving people with HIV the information they needed to make their own choices about which treatments to pursue, and “to show the system what it could be doing.” She noted that the group—“a very good community-based FDA,” as she put it—grew out of its founders’ will to live and willingness to organize. “The underground is brilliant,” Cooper told me in 1995. “It’s an incredible thing—and it’s what happens when a community wants to survive.”³⁶²

Nevertheless, said Hodel, the buyers’ clubs didn’t represent a viable long-term solution to the desire of people with life-threatening illness for access to emerging or experimental treatments. “My intention,” he said, “was always to promote a larger, more systemic response to get the system to adjust, rather than to create another piece of the health care delivery system. That was not our intention.”

One reason the clubs could not be viewed as the best solution was that not all people with HIV had access to them. As Hodel put it, “The buyers’ clubs fulfilled a need for people who were relatively plugged in, had access to this kind of information, and had the wherewithal to negotiate that kind of transac-

³⁶². Sally Cooper, interview with author, New York City, 29 April 1995.

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tion. But it didn't really take care of a lot of other people who still deserve to be helped."³⁶³

A group of people with AIDS who met regularly at the Metropolitan Community Church, on Eureka Street in San Francisco, to share support and information about possible treatments, decided they weren't going to wait to get drugs from the FDA. Like the PWA Health Group in New York, the group decided to bring unapproved drugs into the country and make them available to people with AIDS through a buyers' club that they formed in April 1987 and named the Healing Alternatives Foundation. A couple of them began to smuggle a drug called ribavirin from Mexico. Then it was AL-721 and dextran sulfate. "They would bring these drugs back to the church," explained Matt Sharp, the foundation's director at the time of our 1995 interview, "and after their treatment exchange meeting they would go and purchase some of the drugs that were being smuggled into the country."

Demand was huge, and the foundation soon became a combination health-food store and pharmacy, selling at reasonable prices vitamins, nutritional supplements, and "foreign products" (unapproved drugs). Underscoring its role as simply a conduit for possibly useful therapeutics, a brochure for the organization noted, "H.A.F. makes no medical claims for the products it distributes." As Sharp explained, "The most important issue for us is safety, because we want to make sure that we have clinical trial data that show that whatever somebody brings to us is safe. After that, in terms of efficacy, we feel like it's up to the individual patient to make the decision. As long as it's safe, they should be able to try anything they want."

³⁶³. Derek Hodel, interview with author, New York City, 27 April 1995.

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Matt Sharp himself was typical of the kind of self-motivated client who paid the nominal one-dollar membership fee to use the foundation's services. Nearly nine thousand people had become members to the point when I interviewed Sharp, in 1995, at the foundation's modest offices on Market Street. He described the road that had taken him from his home in the Midwest to San Francisco, and his own sense of empowerment. Sharp was a thirty-five-year-old professional ballet dancer in Oklahoma City when he was diagnosed with AIDS. Although he loved dancing and wanted to continue, he kept thinking he should move to San Francisco, where he would have excellent care and access to the latest information. The AIDS support group he was in didn't help; everyone in it had mostly resigned themselves to inevitable death. Looking and feeling healthy at the time we met, Sharp justifiably cited himself as an example of "what motivating yourself will do to keep you alive."³⁶⁴

Of the buyers' clubs throughout the country by the mid-nineties, only three held tax-exempt status by the IRS: the PWA Health Group, Healing Alternatives Foundations, and the AIDS Treatment Initiative in Atlanta. Tom Blount founded the Atlanta buyers' club in 1991. Blount, an architect, became a full-time AIDS activist after his business partner was diagnosed and died in 1986, and his own lover tested positive. "I think the first thing I did was call Project Inform's 800 number," Blount recalled. "I called AID Atlanta, and it was all sort of 'let's hold hands and sing Kumbaya on the way past the graveyard.'" Blount was impatient with this palliative approach and determined to save his partner's life. "I didn't want to feel good about this," he said. "I wanted to find a way to cure it."

³⁶⁴. Matthew Sharp, interview with author, San Francisco, 1 February 1995.

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Blount's lover, Jim, died only a month before our September 1995 interview, after exhausting every possibility that the resourceful activist could muster through his nationwide network of contacts in the scientific community and treatment underground. Jim had an HIV-related brain tumor. An Internet search turned up only one clinical trial, at the University of Southern California, an old chemotherapy that had been discarded thirty years earlier because of its side effects. The doctor who studied the drug had only about a 22 to 30 percent success rate in destroying the central nervous system lymphoma, which is what Jim had.

Despite the low success rate and possible side effects, Blount wouldn't give up. "All the doctors had thrown up their hands," he said. "But I forced it through." Blount arranged to have the drug flown in from L.A. and given to Jim. Days of waiting and watching followed. An M.R.I. ten days later revealed that the drug had had no effect. Blount said, "That was the day I gave up [hope for Jim's survival]. After ten years of this epidemic, we never gave up. I only had to spend two and a half days of hopelessness, and I consider that a real blessing. Most people give up the moment they're declared positive."

As Blount's and his partner's experience demonstrated, there were no instruction manuals to guide the way in dealing with AIDS. Faith, and a willingness sometimes to take potentially serious risks, is all there was for many people with AIDS. "It's like swinging through a jungle in the middle of the night, from vine to vine," said Blount. "You have to let go at the high point and reach out and grab whatever you can out there. I have swung through that jungle in the night for ten years, and there's always been something." Despite his lover's death and a seri-

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ous setback to his own faith in an eventual cure, Blount added, “There is a way to get through this, I know there is.”³⁶⁵

Michael Callen, like all his fellow PWA activists and their uninfected supporters, pursued the same belief. But their faith and involvement carried a steep price in terms of their own emotional well being. In his book *Surviving AIDS*, Callen observed that one of the consequences of being involved in the PWA self-empowerment movement was having to endure the deaths of new friends. The energy and drive required was terrific for someone like Callen, who was living with HIV infection, busy following leads on promising treatments to try to save himself, and at the same time trying to inspire hope and pass along information to other people with AIDS.

One way that Callen, Bobbi Campbell, and other gay men with AIDS and their supporters worked to empower their fellow PWAs was in the creation of the National Association of People with AIDS (NAPWA), which they founded after the 1983 Denver AIDS forum. Located just outside of Washington, DC, NAPWA continues to serve as “the voice of the people,” as its literature describes the organization. The Denver Principles of PWA self-empowerment are its “guiding light.” Advocating on behalf of people with HIV in the nation’s capital, providing speakers who share their personal stories at schools and businesses throughout the country, creating a mail-order prescription drug service called MedExpress (now a separate, independent company), organizing various national conferences and training institutes, “NAPWA’s mission is broad but its vision is simple—a world without AIDS,” as the group’s *Community Report* has put it.

³⁶⁵. Tom Blount, telephone interview with author, 27 September 1995.

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Like its founders, NAPWA is committed to disseminating accurate information to and about people with HIV with the simple belief that information is power, and that having information gives one the ability to live as well and as long as possible with HIV. In 1995, the group launched a national campaign to encourage people to be voluntarily tested for HIV, declaring June 27 to be “National HIV Testing Day.” NAPWA believes the information about one’s HIV antibody status is an essential first step in preventing oneself from becoming infected if HIV-negative, and both preventing others from becoming infected and receiving appropriate medical attention if HIV-positive.³⁶⁶

While its fiscal condition has fluctuated over the years—in late 1996, the organization had to cut back on staff and programs because of a significant shortfall in projected income³⁶⁷—NAPWA has played an important role in keeping attention focused on the human face of people living with HIV.

In 1992, NAPWA released a report that offered the most comprehensive look to that point at the needs and problems of people living with HIV. Drawing upon survey responses from more than eighteen hundred people with HIV, the report, *HIV in America*, revealed that in addition to the challenge of simply trying to stay well, one in five people with HIV had been a victim of violence at home or in the community. More than half the respondents said they had difficulty in obtaining and paying for health care. Out of every ten people with HIV infection, nearly three were living on less than \$500 a month, and another three lived on \$500 to \$1,000 a month. As if it wasn’t challenging

³⁶⁶. National Association of People with AIDS, *Community Report FY 95* (Washington, DC: NAPWA, 1995).

³⁶⁷. Brian O’Connell, “NAPWA Budget Woes Force Layoffs,” *Washington Blade* (4 October 1996), 1.

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enough to obtain and pay for health care, the report noted that fear and discrimination against people with HIV by health care providers continued to stand in the way of receiving appropriate care.³⁶⁸

A. Cornelius Baker, NAPWA's executive director from 1996 until leaving in 2000 to become director of D.C.'s Whitman-Walker Clinic, is a Black gay man with a mirthful laugh. He has been active both in the federal government and in the local Washington, DC, community, where he helped to organize a group called Best Friends, to provide emergency funds to Black and Hispanic men with AIDS. Baker had been living with HIV for a dozen years when I interviewed him in March 1995 for the original edition of this book. His remarks illustrate both his own character and NAPWA's advocacy role.

On a day in early spring, Baker said, "Today is such a beautiful day, and I think about the daffodils. It's another sign that after the winter there still will be some life. I think we have to look for our signs. For me one of the signs now is whenever any friend tells me they're negative, or whenever I meet somebody who has been positive for fifteen years and they're still healthy. Or when I meet an eighteen-year-old gay man, and I think that in the midst of all this horror here's a person who says, 'I will be what I am.' Those are all signs of hope. It gets you through."³⁶⁹

³⁶⁸. National Association of People with AIDS, *HIV in America: A Profile of the Challenges Facing Americans Living with HIV* (Washington, DC: NAPWA, 1992).

³⁶⁹. A. Cornelius Baker, interview with author, Washington, DC, 21 March 1995.

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Despite the lift provided by taking charge of their lives, living with HIV and losing friends and loved ones to AIDS was sometimes too much, even for PWA activists. When Bobbi Campbell died in 1984, Dan Turner, his early partner in the fight against AIDS, thought to himself, "Where will we get another Bobbi? Bobbi was not only fighting for himself; he was fighting for all of us. And when he went into battle, he was carrying the standard for all of us. And then suddenly he was gone." Turner added, "I cried for fifteen minutes solid when I heard Bobbi had died. I remembered him wearing his 'Survive' button."³⁷⁰

³⁷⁰. Michael Callen, *Surviving AIDS* (New York: HarperCollins, 1990), 121.

SEVENTEEN

On July 3, 1985, a Boston furniture salesman became the first person with AIDS to take AZT, a drug that had been shelved as a useless cancer treatment since the 1960s.³⁷¹ The date is significant because it was precisely four years to the day after the first mention of the epidemic in the “newspaper of record,” the *New York Times*, when many gay men first learned of the disease that would kill so many of them and forever change their world. Having passed the bare minimum first phase of the federally mandated three-phase drug development process, AZT was deemed “safe” after being tested in only nineteen AIDS patients.

Next came the phase-two trial, to determine the drug’s efficacy and correct dosage. A 1986 study of 282 patients with AIDS and a milder, preliminary form of the illness then referred to as AIDS-Related Complex (ARC), found that those given AZT lived longer and had fewer of the opportunistic infections associated with AIDS. Forty-five subjects being given placebo developed opportunistic infections, compared with twenty-four who were on AZT.

By the end of the study, nineteen of the 137 patients who were given placebo, and only one of the 145 taking AZT, had died. The causes of death of those on placebo read like a laundry list of the various infections that run amok in the body in the presence of an immune system ravaged by HIV. *Pneumocystis*

³⁷¹. Peter S. Arno and Karyn L. Feiden, *Against the Odds: The Story of Drug Development, Politics, and Profits* (New York: HarperCollins, 1992), 42.

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carinii pneumonia (PCP) killed eight; disseminated *Mycobacterium avium-complex* four; cryptococcosis two; cerebral toxoplasmosis two; disseminated cytomegalovirus infection one; B-cell lymphoma one; and another individual died from severe debilitation with wasting. The one person on AZT who died was the casualty of disseminated cryptococcosis.

At the beginning of the study, participants already were well along in the course of HIV infection, evidenced by their baseline CD4 counts. The normal count of these white blood cells (commonly called T-cells, they are an important part of the immune system and the primary target of HIV) is around one thousand per cubic millimeter of blood. For the AIDS patients who entered the study, the damage to their immune system was evident in their dangerously depressed CD4 counts: an average of only 65.6 for those on AZT, and 77 in those on placebo. Even those who had AIDS-Related Complex had an average of less than two hundred CD4 cells, which today is the cutoff point below which an HIV-positive individual is diagnosed as having AIDS. The researchers, led by University of Miami scientist Margaret Fischl, noted that the slowed pace at which CD4 cells were destroyed by HIV in those who were taking AZT warranted further investigation of the drug's possible benefits for individuals with HIV but without symptoms.³⁷²

The monitoring board overseeing the AZT development process for the Food and Drug Administration (FDA) recognized that AZT was having what at the time seemed a dramatic effect in the early trials. In September 1986, the "blind" was taken off the study, and patients who had received placebo

³⁷². Margaret A. Fischl, MD, et al., "The Efficacy of Azidothymidine (AZT) in the Treatment of Patients with AIDS and AIDS-Related Complex: A Double-Blind, Placebo-Controlled Trial," *New England Journal of Medicine* 317 (1987): 185–91.

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were offered AZT. Burroughs Wellcome, the pharmaceutical company that held the patent on AZT, provided the drug, free of charge, to some forty-five hundred people with AIDS between September 1986 and March 1987—about a third of all those known to be living with AIDS in this country at the time.

Phase three, in which a drug's safety and effectiveness is tested in a larger group of patients, was waived for AZT. Instead, Burroughs Wellcome rushed to submit all the new drug application paperwork required by the FDA to consider a drug for approval. Ellen Cooper, who at the time was director of the FDA's Antiviral Drug Division, overseeing the development of AIDS drugs, recalled, "The company worked around the clock to get the data into shape to submit to the FDA. Then basically we worked almost around the clock to approve it."³⁷³

On March 19, 1987, the FDA approved AZT, despite reservations over the limited knowledge about the drug, its hasty six-month phase-two trial, and the lack of a phase-three trial. Desperation for any kind of treatment meant that corners were cut throughout the process. Their consequences would become apparent in the coming years as patients suffered sometimes serious side effects from the high dosages of AZT prescribed early on. More importantly, the drug eventually would prove to have limited effectiveness when used as a "mono-therapy." In the meantime, questions about AZT's speeded-up approval, and the right of Burroughs Wellcome to have an exclusive claim on a drug that had been created by taxpayer-funded government scientists, would keep the political waters roiling for a long time to come.

³⁷³. Ellen Cooper, MD, interview with author, Bethesda, Md., 4 December 1996.

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For the time being, however, the importance—as much symbolic as medical—of having some kind of treatment to offer patients, and the pressure to make it available as quickly as possible, was tremendous. San Francisco internist William F. Owen, Jr., who had used AZT on an experimental basis with a number of his AIDS patients, said, “For the first five years of the epidemic, there was so little we could offer to patients once they were diagnosed. Now the medical profession has *something* to offer. It may not sound like much, but the chance for some quality time is really important to patients who, just a few months ago, had nothing.”³⁷⁴

Just over a week before the FDA approved AZT, Larry Kramer addressed a group of about 250 men and women at the Gay and Lesbian Community Center in New York on March 10, 1987. With thirty-two thousand AIDS cases in the country by that point—nearly a third of them in New York alone—Kramer reminded the group of his famous 1983 article “1,112 and Counting.” Rephrasing the article that first alerted many gay people to the political ramifications of AIDS, Kramer warned, “If my speech tonight doesn’t scare the shit out of you, we’re in real trouble. If what you’re hearing doesn’t rouse you to anger, fury, rage, and action, gay men will have no future here on earth. How long does it take before you get angry and fight back?”

Kramer noted that FDA approval of a new drug could easily take ten years. “Ten years!” he said. “Two-thirds of us could be dead in less than five years.” Kramer criticized the FDA’s speeded-up trials of AZT and plans for the drug’s imminent approval. One of his biggest targets was the FDA itself and what he called the “exceptionally foolish” double-blind studies ordi-

³⁷⁴. Sari Staver, “AZT Turnaround,” *American Medical News* (20 February 1987), 14.

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narly used to test drugs. (The studies are called “double-blind” because neither the patient nor the doctor knows whether the patient is getting the actual drug being tested or simply a placebo.) Kramer pointed out that people facing a life-threatening illness like AIDS would lie if they had to in order to get hold of a promising treatment. Cutting to the chase in his inimitable way, Kramer raised a challenge to the FDA: “We’re willing to be guinea pigs, all of us,” he thundered. “Give us the fucking drugs!”³⁷⁵

Formed in response to Kramer’s rousing speech, ACT UP wasted no time in planning its first action for the twenty-fourth—five days after the approval of AZT. At the demonstration on Wall Street, the group distributed thousands of copies of an op-ed article by Larry Kramer that had run in the *New York Times* the previous day. “There is no question on the part of anyone fighting AIDS that the FDA constitutes the single most incomprehensible bottleneck in American bureaucratic history,” wrote Kramer. “Double-blind studies were not created with terminal illnesses in mind,” he noted, calling for the FDA to make experimental AIDS drugs available on a “compassionate usage” basis.³⁷⁶ In response to Kramer’s article, an effigy of FDA Commissioner Frank Young was hung in front of Trinity Church.

ACT UP explained its anger in a fact sheet that said, “For twelve long months AZT was proclaimed as promising, but in such short supply that it had to be rationed to a very few mortally ill patients. Once Burroughs Wellcome was licensed to distribute AZT, supply for thirty thousand was immediately on hand!” AZT became the most expensive drug ever marketed to

³⁷⁵. Larry Kramer, *Reports from the holocaust* (New York: St. Martin’s Press, 1989), 127–39.

³⁷⁶. *Ibid.*, 140–44.

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that point when Burroughs Wellcome seemed arbitrarily to slap a \$10,000 price tag on a year's supply of the drug, putting it well beyond the reach of most of the people who needed it.

ACT UP noted the fact that many people with AIDS, if not already poor when they were diagnosed, were financially devastated as a result of not being able to work, had lost their health insurance if they had it, and were rejected by health insurers if they didn't. "Every major insurance company routinely denies benefits to people with AIDS or at risk for AIDS," said the group. "That leaves only taxpayer-funded Medicaid, which will not pay for any form of experimental therapy."³⁷⁷

Now that AZT had been approved, AIDS activists finally had something concrete to rally around. Besides ACT UP in New York, a group calling itself Citizens for Medical Justice demonstrated against Burroughs Wellcome in San Francisco. After briefly changing its name to AIDS Action Pledge, CMJ became the San Francisco chapter of ACT UP.

In cities throughout the country, and in Europe, ACT UP chapters sprang up, leaderless and only informally affiliated with one another. For its first six months, ACT UP's main goal was to get "drugs into bodies."³⁷⁸ They were determined to shake loose any experimental therapies that might have been caught in the clogged bureaucratic pipeline at the FDA or the National Institutes of Health.

As the result of pressure from ACT UP, Burroughs Wellcome by the end of 1987 reduced the price of AZT by 20 percent to

³⁷⁷. Douglas Crimp with Adam Rolston, *AIDS DemoGraphics* (Seattle: Bay Press, 1990), 28, 37.

³⁷⁸. Ibid.

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\$8,000. Even so, *Barron's* predicted that the pharmaceutical giant would earn \$200 million on AZT in its first year alone. Within four years after AZT's approval, Burroughs already had earned \$1 billion on the drug that had been developed at the expense of the American people.³⁷⁹ The company's extraordinary profits on AZT were the catalyst that finally sparked the interest of other drug manufacturers that had, until then, seen AIDS as a waste of their time and money.

Among ordinary citizens infected with or at risk for HIV, the availability of a drug that had even some promise for treating the virus was the catalyst for a political movement focused largely on pushing for the speedy approval and availability of new drugs to treat HIV and its attendant infections. As Peter Arno and Karen Feiden observe in *Against the Odds*, "The approval of AZT seemed to unleash a potent force into the world. Patient empowerment—the refusal to be passive victims, the insistence on fighting the system that would pronounce their doom, the willingness to take matters in their own hands—became a reality."³⁸⁰

³⁷⁹. A 1988 report by the U.S. House of Representatives Committee on Government Operations (*AIDS Drugs: Where Are They?*) notes, "NCI [National Cancer Institute], along with NI-AID [National Institute of Allergy and Infectious Diseases], not only participated heavily in the development of the drug [AZT], but also supplied Burroughs Wellcome with large amounts of thymidine, a scarce and expensive ingredient. However, because the government has granted the company an exclusive patent on AZT, the government will not share in profits from its sale, nor is it in a position, under current law, to affect the cost of the drug to the public."

³⁸⁰. Arno and Feiden, *Against the Odds*, 60.

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Since its creation in 1927, the Food and Drug Administration has overseen the licensing, research, and regulation of foods, drugs, cosmetics, and medical devices in the United States. The 1938 Food, Drug, and Cosmetic Act made it illegal to market a drug in the US until it is proven safe. In 1962, Congress extended the FDA's mandate through the Kefauver amendments to the Food, Drug, and Cosmetic Act, requiring not only safety but also proof that a drug's claims of efficacy are legitimate.

Not long after AZT's approval, FDA Commissioner Frank Young in June 1987 announced the agency's new regulations allowing the use of investigational new drugs (IND) to treat AIDS even as they were being studied in clinical trials. The treatment IND, as it was known, allowed patients to receive drugs that were safe and possibly effective while the companies testing them completed controlled trials and compiled, analyzed, and prepared study data for presentation to the FDA. Despite the expectations of a flood of new drugs that activists presumed were stuck in the pipeline at NIH and FDA, the truth was, there simply weren't any. In fact, AZT would remain the only FDA-approved treatment for HIV infection until 1991.

At the July 1988 national gay and lesbian health conference, in Boston, FDA Commissioner Young announced that the agency would permit individuals to import small quantities of unapproved drugs for personal use in trying to treat AIDS. The "new" policy merely codified the FDA's longstanding compassionate-use policy, essentially giving a stamp of approval to what buyers' clubs already had been doing for a year at that point. Said Young, "In fighting AIDS, FDA is committed to two important, but sometimes conflicting principles—compassion and good science."

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As the federal government had already demonstrated with respect to prevention, neither compassion nor good science counted when it came to politics. For the moment, though, gay people were pleased that their efforts seemed to have been acknowledged. Three rows of ACT UP protesters holding signs saying “FDA, You’re Killing Me,” and an audience inclined to be hostile toward the commissioner, were taken by surprise, and responded enthusiastically to Young’s announcement with a standing ovation.

But ACT UP wanted more. The Group’s Treatment and Data Committee prepared an *FDA Action Handbook* and conducted teach-ins for ACT UP’s general membership, educating activists about the FDA and its drug approval process. When ACT UP demonstrators from across the country converged on FDA’s Rockville, Maryland, headquarters on October 11, 1988, they knew what they wanted and articulated it forcefully to the news media.

Among their demands, ACT UP insisted that the FDA shorten its drug approval process to “ensure immediate free access to drugs proven safe and theoretically effective,” eliminate double-blind placebo trials and instead measure new drugs against other approved or experimental drugs, and “include people from all affected populations at all stages of HIV infection in clinical trials.” ACT UP contended that in the case of a new disease like AIDS, the testing of new drugs itself was a form of health care—and that everyone should have the right to receive health care.³⁸¹

Eight days after the demonstration, the FDA announced new regulations to speed up the drug approval process, formalizing the expeditious process that had been used the previous

³⁸¹. Crimp and Rolston, *AIDS DemoGraphics*, 76–83.

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year to move AZT quickly through the pipeline to the market. Besides the changes at the FDA, the 1988 demonstration was “one of the most cataclysmic and definitely milestone activist events of the eighties,” said Robert Bray, who assisted in promoting the event to the media in his role as director of public relations for the Human Rights Campaign Fund (today HRC), the Washington-based gay lobbying organization. Looking back, Bray said, “I would say the FDA action represented not only an escalation of activist tactics, but a newfound professionalism, media savvy, and strategic organizing of AIDS activism.”³⁸²

It also represented an important shift in the tactics used by activists, as they realized that venting their rage outside of empty government buildings could only go so far in changing the policies and procedures formulated and followed by the federal agencies housed inside them. FDA’s agreement to streamline the drug approval process had at least as much to do with meetings between agency officials and key members of ACT UP as it did with the verbal drubbing by demonstrators who had learned how to manipulate the media to advance their cause.

David Barr, a member of ACT UP’s Treatment and Data Committee, said, “Not only had we been able to show our fire-power out on the street, but when we sat down at the table we had a list of issues that we understood.” Barr said that while ACT UP’s demonstration was “theater,” the small, select group of informed activists who met with the FDA had to distill their issues to a short list of priorities. “We learned how to do a

³⁸². Robert Bray, interview with author, San Francisco, 2 February 1995.

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meeting,” he said.³⁸³ As it turned out, this particular skill would serve the activists far more effectively than the talent for drama they continued to display over the next couple of years.

As activists worked both inside and outside the federal government to push for more and better AIDS drugs, two innovative research programs looked at experimental treatments in untraditional settings in local communities, rather than in university hospital settings where medical research typically is conducted.

In San Francisco, Donald Abrams helped to launch the County Community Consortium (CCC) in March 1985. A group of physicians from the Bay area who originally came together to talk about their AIDS patients and experimental drug protocols, CCC members soon decided to design a clinical drug trial that they could conduct from their own offices. After AZT became available, the group launched a study of aerosol, or inhaled pentamidine, a drug that had showed promise in preventing *pneumocystis carinii* pneumonia—the leading killer of people with AIDS. A hundred patients were enrolled at twelve sites throughout the Bay area, with sixty-nine physicians participating in the study. Abrams said the federal government refused to provide funding for the CCC study because “it was too novel and too community-based.”³⁸⁴

Meanwhile, in New York, the PWA Coalition organized their own treatment research program, called the Community Re-

³⁸³. Steven Epstein, *Impure Science: AIDS, Activism, and the Politics of Knowledge* (Berkeley: University of California Press, 1996), 226.

³⁸⁴. Donald I. Abrams, MD, telephone interview with author, 17 July 1995.

VICTORY DEFERRED

search Initiative. Larry Kramer called it “an historic attempt by the gay community to test drugs on ourselves.”³⁸⁵ Unlike San Francisco’s CCC, which was built around a network of doctor’s offices and linked to San Francisco General Hospital, CRI was located in rooms adjoining those of the PWA Health Group, on West Twenty-Sixth Street in Manhattan. Its goal was to test drugs in a community setting—rather than in the kind of impersonal, intimidating medical research centers. The goal of CRI’s founders—PWA activists Michael Callen and Tom Hannan, their physician Joe Sonnabend, and Mathilde Krim, the director of the American Foundation for AIDS Research—was, as Callen described it, to conduct “rigorous scientific research on promising AIDS therapies in a community-based setting faster and more cheaply than traditional systems do.” In keeping with the Denver Principles, Callen said, “CRI utilizes study designs that are sensitive to the needs of PWAs, because PWAs and physicians who care for us are involved at every level of the decisionmaking process.”³⁸⁶

A group of people with AIDS met in May 1987 with Dr. Anthony Fauci, director of the National Institute of Allergy and Infectious Diseases (NIAID), to plead that the government issue guidelines advising physicians to use inhaled pentamidine to prevent *pneumocystis* in their AIDS patients. Fauci refused. Michael Callen announced that people with AIDS would test inhaled pentamidine themselves. Ninety New York City physicians and two hundred people with AIDS agreed to participate in the study.

Joe Sonnabend was already using Bactrim to treat PCP in his gay patients with AIDS who had the deadly pneumonia, the

³⁸⁵. Kramer, *Reports from the holocaust*, 209.

³⁸⁶. Callen, *Surviving AIDS*, 10.

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leading killer of people with AIDS at the time. Sonnabend was a principal investigator for aerosolized pentamidine. “But,” he told me, “Bactrim had already been proven to prevent PCP” in others with suppressed immune systems, such as kidney dialysis patients and children with leukemia. Sonnabend said he was “beaten up” for giving AIDS patients Bactrim when all the interest was now focused on inhaled pentamidine. Sonnabend still calls it “absolutely shocking” that the government insisted on trying the new drug when the existing one could have saved lives. “If you were getting a kidney transplant, you’d get Bactrim,” said Sonnabend. “If you were a gay guy with AIDS, and got PCP, you died.” Many gay men died from PCP as a result.³⁸⁷

Two years later, on May 1, 1989, Lyphomed, the drug company that held the patent on pentamidine, presented data from the CCC and CRI studies to the FDA. Physician-researchers from the CCC in San Francisco spoke about the effectiveness of inhaled pentamidine, and speakers from New York’s CRI offered additional information about the drug’s safety.

In a final, personal plea, Michael Callen told the FDA committee, “I have witnessed firsthand the tremendous, unnecessary suffering caused by PCP—people with AIDS gasping for breath, twitching on respirators, unable to speak.” He noted that, despite the desperate need for prophylaxis against *pneumocystis* and the promise that inhaled pentamidine had showed when used by physicians, “No one in the AIDS establishment seemed to have any interest in the clinical observations of the physicians on the front lines of this epidemic.” As was the case with the buyers’ clubs, Callen said, “The AIDS community has

³⁸⁷. Joseph Sonnabend, MD, telephone interview with author, 27 July 2010.

VICTORY DEFERRED

done an end run around federal incompetence and indifference.”³⁸⁸

Based upon the information provided by the CCC and CRI, the FDA committee voted unanimously to approve aerosol pentamidine to prevent *pneumocystis* pneumonia—the first time a drug had ever been approved based on research conducted at the community level. Although the research wasn’t as “pristine” as traditional academic medical research used to decide for or against a new drug, Ellen Cooper, the former FDA official, said, “I guess the lesson is, first, that important information can come from rather primitive trials as long as certain key elements are followed,” including randomization, two “arms” of the study that are different enough to detect whether one was superior over the other, and reasonable “endpoints,” in this case the development of PCP.³⁸⁹

As much as the scientific knowledge generated by the community-based studies, Cooper said, “just doing it was important.” Important because it showed that there are alternatives to the traditional way of conducting clinical research—in the cases of the CCC and CRI, involving both the doctors who actually cared for AIDS patients and the patients themselves in the design of the research studies. By putting research in the hands of the doctors on the front lines providing care, and the people with AIDS receiving it, community-based trials emphasized that the need to gather scientific information can be balanced with not merely caring for, but also caring about, patients as human beings, friends, and neighbors. The active involvement of people with AIDS in community-based trials served—like the support groups, coalitions, and buyers’ clubs they had

³⁸⁸. Callen, quoted in Arno and Feiden, *Against the Odds*, 118.

³⁸⁹. Ellen Cooper interview.

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formed—to strengthen their own will to survive. As Peter Arno and Karen Feiden put it, “Because it empowered patients and fostered strong ties with their physicians, community-based research offered, above all else, something whose value could not be measured: a sense of hope.”³⁹⁰

The Presidential Commission on the HIV Epidemic mentioned the CRI in its June 1988 report, urging the federal government to fund similar community-based AIDS research. An October 1988 congressional report quoted CRI director Tom Hannan as saying, “Open communication and trust are more common in relationships between the community physician and the patient than in those between university-based investigators and clinical trial participants whom they may see once every three months or less frequently unless the patient is hospitalized. The AIDS patient is more likely to believe his or her personal health is a top priority with the community physician than with the investigator whose first goal is to study the effects of the drug.”³⁹¹

Addressing the matter of whether care and research are mutually exclusive categories, the House of Representatives Committee on Government Operations noted in its 1988 report, *AIDS Drugs: Where Are They?* that in conducting research on cancer, the federal government had no problem resolving this conflict. “HIV infection,” said the report, “may have brought us to the time when it is necessary to reevaluate the dichotomy between research and treatment for all life-threatening conditions.” It went on to quote from an earlier report, produced by

³⁹⁰. Arno and Feiden, *Against the Odds*, 124.

³⁹¹. US House of Representatives, Committee on Government Operations, *AIDS Drugs: Where Are They?* (Washington, DC: Government Printing Office, 1988).

VICTORY DEFERRED

NIAID in January 1988, which said, “The primary intent of [NIAID’s clinical trials program] is not the delivery of medical care to AIDS patients, although providing excellent medical care is a component of every good clinical trial.”³⁹²

The committee wasn’t satisfied with that assessment. “In the context of AIDS and other life-threatening conditions,” it insisted, “clinical trials cannot be considered solely scientific experiments. Access to clinical trials becomes access to therapy, access to quality health care, and for many, access to hope.”

Of the twenty-five thousand Americans known to be living with AIDS at the time—with as many as 1.2 million more estimated to be HIV-infected—the committee noted that only about forty-six hundred, or 0.3 percent, of the estimated total had participated in clinical trials.³⁹³ Put another way, this meant that 99.7 percent of Americans believed to be infected with HIV did not have access to drugs that could potentially save their lives.

Following the recommendation of the presidential commission, Congress in the fall of 1988 approved a \$6 million pilot program to conduct clinical trials in local hospitals, health centers, doctors’ offices and clinics, and drug treatment facilities around the country, to be managed by NIAID. The Terry Bein Community Programs for Clinical Research on AIDS (CPCRA) were intended to complement NIAID’s AIDS Clinical Trials Group (ACTG), which began in 1987 to conduct trials in academic medical centers across the country.

³⁹². AIDS Clinical Trials Advisory Group, *Final Report* (22 January 1988), 4.

³⁹³. US House of Representatives, Committee on Government Operations, *AIDS Drugs: Where Are They?*

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In its first year the CPCRA supported eighteen treatment research programs based in fourteen cities where large numbers of people with AIDS lived and received medical care. Local physicians and their patients were enlisted in clinical trials of new drug therapies. The program was designed especially to reach out to Blacks, Hispanics, women, and intravenous drug users—overrepresented in the AIDS population, but grossly underrepresented in clinical research.

Advocates interpreted the new support for community-based research as an acknowledgment of what they had been criticizing as a flawed clinical trials process. By reducing the cost of research on prospective AIDS drugs, and providing access to promising treatments directly through the physicians who were caring for AIDS patients, the advocates felt community-level, grass-roots, research would speed up the historically glacial pace of the three-phase drug development process required by the FDA. As Martin Delaney said, “The clinical trials model we use is designed for the convenience of the FDA and drug companies. It has nothing to do with making patients better. It has only to do with licensing a product.”³⁹⁴

Physicians were concerned about the drugs and other substances their AIDS patients were taking, many of them available through the drug underground and buyers’ clubs, and saw community-level research as an opportunity to evaluate these agents.³⁹⁵

³⁹⁴. Delaney interview.

³⁹⁵. Calvin Cohen, Abby Shevitz, Kenneth Mayer, “Expanding Access to Investigational New Therapies,” *Primary Care* 19 (March 1992): 87–96.

VICTORY DEFERRED

Despite the benefits of the research, it was probably inevitable that, at some point, patients and advocates would be brought up short by the guesswork and lack of hard information used in trying untested treatments. Compound Q, the derivative of a Chinese cucumber root, did precisely that.

After promising animal studies, the FDA approved phase-one clinical trials, to be headed up by Paul Volberding at San Francisco General Hospital. Word about the animal studies spread quickly. Martin Delaney, together with San Francisco pediatrician Larry Waites and allergist Al Levin, decided to launch their own four-city trial, sponsored by Project Inform. Jim, Corti, who had been nicknamed “Dextran Man” for his role in smuggling dextran sulfate into the country, now traveled to China to obtain Compound Q for the study.

Delaney recalled the reasoning behind the underground trial, launched in May 1989. “Our fear was that if the drug was as helpful as we hoped, it would be forever before we got the answer on it,” he said. “If it was as dangerous as we feared, large numbers of people could be hurt from self-experimentation.”³⁹⁶

Unfortunately, a participant in the Project Inform study, Robert Parr, died on June 24, 1989. A national spotlight was shined into the secretive world of the AIDS drug underground. Delaney claimed that Project Inform was simply monitoring patients who were being treated with Compound Q, rather than conducting a study per se. However it was defined, the Compound Q study cut corners that threatened the credibility of community-based research. Besides using a form of the drug that the FDA would not consider pure enough, the Project Inform study didn’t bother to obtain the approval of the local review boards that are convened to protect the interests of partic-

³⁹⁶. Arno and Feiden, *Against the Odds*, 209.

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ipants in scientific research. These institutional review boards (IRBs) include doctors, scientists, clergy, and others who determine whether a study has sufficient promise to let participants assume whatever risks may be involved, and ensure that they are informed of any significant aspects of the research. Still, Delaney argued that the physicians involved deserved credit for at least monitoring the use of the drug, which he said patients would have used anyway, and with potentially even more dire consequences.

The FDA asked Project Inform to stop the Compound Q trials, and asked Delaney to meet with Ellen Cooper and other FDA officials in Washington. In the meantime, two more participants in the trials died, one a suicide and the other a young New York actor named Scott Sheaffer, who died after surviving three bouts of PCP and numerous opportunistic infections. Michael Callen criticized Project Inform for not having the IRB ethical stamp. Mark Harrington, a member of ACT UP/New York's Treatment and Data Committee, said it was incumbent upon activists who conducted clinical research to meet "the highest standards of scientific integrity and medical care."³⁹⁷

Although he expected to be reprimanded, and possibly even charged criminally in the death of Robert Parr, Delaney instead was surprised and relieved to get the FDA's blessing. On March 8, 1990, the FDA approved Project Inform's plan to move forward with Compound Q, requiring only that it use a synthetic version of the drug and test it on people who had already used it.

Looking back on the troubled, troubling history of this one drug, destined to disappear into the miasma with the many other drugs that ultimately proved ineffective against HIV, Ellen

³⁹⁷. Ibid., 213.

VICTORY DEFERRED

Cooper, who initially had been impressed by Project Inform's data when she met with Delaney at the FDA in 1989, said, "Compound Q is an example of too many risks being taken too quickly."³⁹⁸ Despite the flawed Compound Q study, and his role in sponsoring the renegade drug trial, Delaney's experience of working with the FDA led to a shift in his advocacy.

Rather than being an "outsider," Delaney came to be viewed as an "insider" whose views and connections to the vocal gay AIDS community were actively sought by the federal institutes conducting research on AIDS treatments. This suited Delaney fine. As he explained, "We concluded we'd have a better impact on finding the cure for AIDS not by running trials, but by advising on which trials [would] get done."³⁹⁹

During the hiatus forced by the FDA on Project Inform's Compound Q study, and shortly before Delaney's meeting with the agency, the federal government made an announcement that sent shock waves through the scientific and advocacy communities. Dr. Louis Sullivan, the Secretary of Health and Human Services, announced on August 17, 1989, that a NIAID study had found AZT to be effective in delaying the onset of AIDS in people who were infected but had no symptoms. "To-day we are witnessing a turning point in the battle to change AIDS from a fatal disease to a treatable one," said Sullivan.⁴⁰⁰

A front-page article in the *New York Times* the following day quoted Dr. Samuel Broder, director of the National Cancer Insti-

³⁹⁸. Ellen Cooper interview.

³⁹⁹. Delaney interview.

⁴⁰⁰. Philip J. Hilts, "Drug Said to Help AIDS Cases with Virus but No Symptoms," *New York Times* (18 August 1989), A1.

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tute and one of the first to use AZT against AIDS, as saying, “This is a true breakthrough, and I don’t use those words often.” Excitement was tempered among AIDS advocates, however, by the fact that AZT was still extremely expensive. Thomas Sheridan, speaking on behalf of the Washington, D.C.–based AIDS Action Council, told the *Times*, “The announcement is historically significant because it is the first time that the government is actually offering a treatment for those who are HIV-positive. But now the question is who will pay for these people to get the drug.”⁴⁰¹

ACT UP asked the same question. The answer it arrived at was quite different from what might have come to the minds of scientists or even other advocates: Make Burroughs Wellcome pay for the drug. On September 14, 1989, former bond-trader-turned-AIDS-activist Peter Staley and six other men, dressed in business suits and wearing falsified ID badges, made their way past the guards into the New York Stock Exchange. ACT UP had returned to Wall Street.

As it had done in its first demonstration there two and a half years earlier, the group was once again protesting the cost of AZT. As the opening bell rang at nine-thirty a.m., five of the men chained themselves to a banister and unfurled a banner from a balcony overlooking the trading floor—“Sell Wellcome,” it said. They drowned out the traders with foghorns, and tossed fake hundred dollar bills into the crowd of traders below. On the bills was imprinted the message, “Fuck your profiteering. We die while you play business.” Meanwhile, the other two men snapped photographs, walked outside, and handed them to waiting ACT UP members, who spirited them to the Associated Press.

⁴⁰¹. Ibid.

VICTORY DEFERRED

Of course the actual traders didn't take the situation lightly. "Kill the faggots!" they yelled. Clearly they didn't understand that without access to effective treatment, there would be no need for macho gay bashing; a microscopic organism was already doing a damned good job on its own killing homosexuals. The five protestors were eventually cut loose from the banister and, with the two photographers, arrested. An hour later, though, fifteen hundred ACT UP demonstrators appeared at the scene. There were more foghorns, much yelling, and a leaflet saying "Sell Wellcome, Free AZT" was distributed to startled and fascinated onlookers. ACT UP's "bottom line," said the leaflet, was its demand for free AZT. "With a million and a half Americans infected with HIV and millions more infected worldwide," it said, "Anything Else Would Be Genocide."

Four days later, Burroughs Wellcome announced another 20 percent reduction in the price of AZT. Even at the reduced price of \$1.20 a capsule, though, AZT still would cost more than \$6,000 a year. ACT UP decided to continue its boycott of Burroughs Wellcome's other over-the-counter drugs, affixing "AIDS Profiteer" labels on packages of Sudafed, Actifed, Neosporin, and other common Burroughs Wellcome products.⁴⁰²

⁴⁰². My information about the 14 September 1989 ACT UP demonstration on Wall Street is derived from Arno and Feiden, *Against the Odds*, 135–38, and Crimp and Rolston, *AIDS DemoGraphics* 114–19.

EIGHTEEN

After behind-the-scenes meetings with Larry Kramer during the Fifth International Conference on AIDS, in Montreal in June 1989, NIAID director Tony Fauci announced in San Francisco that month that the institute was going to implement what he called a “parallel track” program for AIDS drug development. One track of the program was the closely monitored clinical trials used to test drugs for efficacy, while the other track would enable physicians to provide drugs that had passed the phase-one test of safety to patients who were unable or unwilling to participate in regular clinical trials because they didn’t meet the entry criteria for the standard trials, the trials were full, or they lived too far away from a trial site.

Kramer lambasted Fauci in his 1989 book *Reports from the holocaust*, but wrote in a conciliatory afterward, “In crusading for the notion of ‘parallel track’—a plan for making experimental drugs available while they are still in Phase Two efficacy protocols under the FDA, in so doing bringing them to us a minimum of two years faster—[Fauci] has indeed become the ‘hero’ George Bush once named him.”⁴⁰³

As a comfortably heterosexual man, Fauci was a far cry from his predecessor at NIAID, Dr. Richard Krause, a closeted homosexual man. After a January 1984 lunch at Krause’s official residence on the bucolic NIH campus in Bethesda, Maryland, Larry Kramer realized the director was, in Kramer’s words, “a closeted gay man so terrified of being discovered to

⁴⁰³. Kramer, *Reports from the holocaust*, 287–88.

VICTORY DEFERRED

be gay that he didn't want AIDS in his fraternity."⁴⁰⁴ Fauci made up for Krause's resistance to involving the institute in AIDS research, going so far as to meet with gay activists and actually involve them in the development of clinical trials. Besides his deputy director, Jim Hill, Fauci had two other openly gay scientists in key positions within NIAID. He hired Jack Killen, formerly a National Cancer Institute researcher who had served as the first paid medical director at Washington, D.C.'s Whitman-Walker Clinic, to help organize the AIDS Clinical Trials Group in 1987. Fauci also hired "Bopper" Deyton in 1986 to help coordinate AIDS research at the institute. Deyton, who was acting director of NIAID's more than \$1 billion per year extramural research program when I interviewed him in 1996, said that Fauci, "saw in me, Jim Hill, Jack Killen and others, a professional interest, but also a personal interest that he wanted."⁴⁰⁵

Killen, director of NIAID's AIDS Division from 1994 until 2001 after serving seven years as deputy director, told me that as a gay man himself, he was concerned about a disease that was striking down people he knew. As a scientist, however, it was a new experience altogether to have members of the patient community actually involved in the decision-making process as well. "You go to an AIDS meeting," he said, "and you see scientists in ties and people with turned-around baseball caps, and you see people who are obviously sick. It brings

⁴⁰⁴. Larry Kramer, *Reports from the holocaust: The Story of an AIDS Activist* (updated and expanded, New York: St. Martin's Press, 1994), 347.

⁴⁰⁵. Lawrence "Bopper" Deyton, MD, interview with author, Rockville, Md., 24 September 1996.

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a very human dimension to this epidemic, which I think anybody going to a scientific meeting about AIDS experiences.”⁴⁰⁶

Robert M. Wachter, professor and chief of the hospital medicine division at the University of California–San Francisco, described the increasingly cooperative relationship between AIDS activists and scientists that began to develop by the late eighties as a “fragile coalition.” But the coalition grew stronger over time in much the same way that successful relationships of all sorts develop: by spending time together, working jointly to get through the rough patches, and always being willing to return to the table because of a shared belief in the ultimate value of the relationship.

Of course another important way that business or social relationships are strengthened is through the breaking of bread together. A series of “working dinners” at Jim Hill’s Capitol Hill home allowed scientists and activists to meet informally and solidify their relationship as they developed simple human comfort with one another.

Hill, a NIAID scientist working on whooping cough and other vaccine research before becoming Fauci’s deputy director in 1986, met Gary MacDonald, the first director of AIDS Action Council and first full-time AIDS advocate in Washington, for dinner in early 1985. Hill later introduced MacDonald to Fauci. In the following years, Hill served as an advance man for Fauci, meeting with AIDS activists, and then arranging meetings for them with his boss. “They always knew that if they wanted to talk to Tony Fauci about something, they could get to him through me,” said Hill.

⁴⁰⁶. Jack Killen, MD, interview with author, Rockville, Md., 28 March 1995.

VICTORY DEFERRED

One of Hill's dinners brought together Fauci and members of ACT UP shortly before a May 21, 1990, ACT UP demonstration at the National Institutes of Health. "That demonstration was fascinating," said Hill. "We had Peter Staley and Mark Harrington here for dinner the weekend before. They had come down to Washington to meet with Tony. They left a package in my house, a big yellow envelope full of stuff. The next morning I FedEx-ed it to Mark Harrington without looking at it. It was the plans for the demonstration."⁴⁰⁷ On the twenty-first, about one thousand demonstrators tossed smoke bombs and chanted "Ten years, \$1 billion, one drug, big deal" and "One AIDS death every twelve minutes." The protest lasted four hours and resulted in eighty-two arrests.

Looking back on those tense years, and the tentativeness on all sides, Tony Fauci told me that, by the time of our 1995 interview, the relationship between scientists and activists had "matured." He attributed its maturation to a fundamentally similar and shared agenda. "I think one of the reasons I've gotten along so well with the gay activists," he said, "is that we've always understood each other. As friendly as we've become—we've actually become very friendly over the years; you can't help that when you're working against or with somebody ten years or longer and you start spending so much time together that you actually become friends—we kind of have a tacit agreement that we will feel comfortable agreeing to disagree on things that we just can't come to agreement on. Yet we agree on a lot more than you'd think we'd agree on."⁴⁰⁸

⁴⁰⁷. James Hill, interview with author, Washington, DC, 24 June 1995.

⁴⁰⁸. Anthony Fauci, MD, interview with author, Bethesda, Md., 14 April 1995.

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Clearly much had changed since the days when Fauci was harshly condemned by Larry Kramer and ACT UP. How did it feel to have been the target of such wrath? Fauci said he didn't take it personally because he realized it wasn't himself as an individual but Dr. Fauci, the Director of NIAID, who was being condemned. "I noticed early on that they were criticizing not me, Tony Fauci, but they were criticizing what they perceived as the establishment—particularly people like Larry. Then I extended myself to them, and tried to listen to the issues that they were criticizing, instead of being very defensive that they were burning *me* in effigy, calling *me* a murderer the way Larry did on the front page of the *San Francisco Chronicle*, and things like that."⁴⁰⁹

So Fauci began to meet regularly with activists like Kramer, Martin Delaney, and members of ACT UP/New York. He said, "That's when we started to develop the bonds and friendship that now, when I get criticized publicly, I know it's an issue they're criticizing, not me. That type of evolution in the relationship between activists and myself has led to what I consider an extraordinarily good relationship between Larry and myself. Interestingly, Larry publicly called me a murderer, but I think the world of Larry; we're actually quite good friends."

The "fragile coalition" had evolved to the point that the lines blurred in everyone's mind as to who was friend and who foe. Said Fauci, "Once they got our attention and they began to understand the issues, and we understood their issues more, they made a decision that it would be best, and they could work better, by actually being part of the process. That's why they're on the advisory committees and ad hoc groups."

⁴⁰⁹. Ibid.

VICTORY DEFERRED

By July 1990, Fauci had announced that activists would have representation on all of NIAID's committees and in the AIDS Clinical Treatment Group, where he established the Community Constituency Group (CCG) to provide them with formal involvement in the ACTG.⁴¹⁰ Were the activists co-opted by effectively becoming part of the system they had criticized so vehemently from the outside? No, said Fauci. "They certainly haven't turned into the metaphorical 'Uncle Toms' at all," he explained. "However, there are other groups of activists who perceive them as having given in to the system, and they prefer to remain more strident on the outside. But now there's much less of that because, I think, even the outside activists realize that there is something to be gained by becoming part of the process so long as you don't give up your principles."⁴¹¹

But principles weren't the only thing the activists had hung on to in their efforts to move the scientific research establishment. Rage—as much from feeling let down in their middle-class expectations of what America owed them as from their grief and sense of impotence against the viral enemy—was something the activists had nurtured at least as closely as the principles they brought to the table. But, as in all adult relationships, rage and temper tantrums ultimately accomplish little more than alienation. In Larry Kramer's 1992 play, *The Destiny of Me*, the playwright's alter ego Ned Weeks—introduced in *The Normal Heart*—seemed to speak for the activists when he said, "When we were on the outside, fighting to get in, it was easier to call everyone names. But they were smart. They invit-

⁴¹⁰. Jonsen and Stryker, *The Social Impact of AIDS*, 96.

⁴¹¹. Fauci interview.

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ed us inside. And we saw they looked human. And that makes hate harder.”⁴¹²

After a December 1990 conference on women and HIV sponsored by NIAID, ACT UP’s Women’s Action Committee proposed a six-month suspension of all face-to-face meetings with government officials. The women were angry at the cozy relationship between some of the men on the Treatment and Data Committee and government officials such as Fauci. But after all the meetings, dinners, and promised slots on the committees and advisory boards, the men from ACT UP’s Treatment and Data Committee weren’t about to give up their new-found access now. As Mark Harrington put it, “As soon as we got the seat at the table, which we had fought for, and which had been a part of our rhetoric for years, there was a faction in ACT UP that didn’t want us to claim it.”⁴¹³

Besides the complications from gender and race, the growing tension between the activists who had become insiders and their fellow ACT UP members was exacerbated by what sociologist Steven Epstein calls “the politics of expertise.” As he explains in *Impure Science*, “It was not simply that some people were working on the inside while others were outside—just as important, those who were on the inside were increasingly mastering specialized forms of knowledge with which their fellow activists on the outside did not come into contact.”⁴¹⁴ Before his involvement with ACT UP, Mark Harrington probably had one of the more extensive backgrounds in science to be found among

⁴¹². Larry Kramer, *The Destiny of Me* (New York: Penguin, 1993), 17.

⁴¹³. Epstein, *Impure Science*, 292.

⁴¹⁴. Ibid.

VICTORY DEFERRED

the activists who fashioned themselves into lay scientists—and that was nothing more than childhood reading of his father's copies of *Scientific American*.

If the goal of the PWA self-empowerment movement was to help people with AIDS live longer by making informed choices, treatment activists represented a kind of hyper-informed version of the PWA activist, devouring information, and now working inside the federal system to influence the choices and policy-making that would affect tens of thousands of Americans. As *AIDS Treatment News* editor John James put it, "Treatment activism takes an immense amount of commitment because of the work involved in becoming informed enough to make a real contribution when you sit down with M.D.s and Ph.D.s"⁴¹⁵

Activists like Harrington and Peter Staley became proficient enough in the arcana of science that they could indeed sit down with doctors and scientists and both speak and listen with intelligence. Although the proposed moratorium on meetings with government officials failed, Harrington, Staley, and a small group of others from the Treatment and Data Committee decided the time had come to part from ACT UP. Frustration with the group's growing fractiousness, often chaotic attempts to make decisions by consensus, uncertain funding, and, more than anything, a desire to work within the system, propelled the men to break away from ACT UP and form the Treatment Action Group (TAG) in 1992. According to an early leaflet for the group, TAG's purpose was to "analyze and watchdog our nation's public health and private AIDS research efforts and advocate for greater efficiencies and resources."

The "TAG boys," as they were described by critics and supporters alike, were businesslike—and they certainly meant

⁴¹⁵. James interview.

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business. As TAG spokesman Spencer Cox put it, “We tend to want to function within the system. Our feeling is you should cooperate with people who are actually doing the research. You also get tired of standing outside of empty buildings and yelling.” Cox, who told me he had “dropped out of ACT UP because [he] was tired of all the infighting,” was one of a second generation of AIDS activists, those who were young enough not to have known a gay community without AIDS—and not to have done anything else professionally before becoming an AIDS activist. As the then twenty-eight-year-old told me, “I had no background professionally before I did this. I came to AIDS straight from college, where my field of study was Victorian literature.”⁴¹⁶ Now his conversation was saturated with esoteric terms from medical science and words like “groovy,” the cutting edge and the retrograde. When he talked about “dating himself” because he could recall the approval of AZT in 1987, the newness of the scientific patina was evident.

TAG’s 1992 report, *AIDS Research at the NIH: A Critical Review*, suggested reforms that were later incorporated into the NIH Revitalization Act of 1993. Among other things, the act created an Office of AIDS Research to oversee all of the federally funded AIDS research conducted on the campus of the National Institutes of Health and in universities, hospitals, community clinics, and private doctors’ offices throughout the country.

TAG participated in a number of prominent federal policy review committees, including the executive committee of NIAID’s AIDS Clinical Trials Group, the Office of AIDS Research’s AIDS Research Program Evaluation Working Group (the Levine Committee), and the National Task Force on AIDS Drug Development. But among treatment activists across the country, the

⁴¹⁶. Spencer Cox, telephone interview with author, 21 November 1996.

VICTORY DEFERRED

group became best known—and, for many, notorious—for its insistence in 1994 that the FDA not approve the first of the protease inhibitor drugs because of the relatively short trial and limited information about its long-term effectiveness. Look at what happened with AZT, argued TAG.

In 1993, a large European trial found that AZT benefited asymptomatic HIV-positive individuals for about a year, after which it neither staved off the progression to AIDS nor prolonged life. In the so-called Concorde study, more than seven-hundred HIV-positive people—the largest and longest study of AZT, which in 1993 was still the most popular drug to treat HIV infection—were randomly assigned to get either AZT or a placebo until they developed symptoms, at which time they were given AZT. As in earlier trials, the Concorde study showed a survival advantage for those on AZT up to one year. But by the third year of the study, most of the advantage had disappeared. Concorde spurred a reassessment of what had become the common practice after 1989 of prescribing AZT when an HIV-positive person's CD4 cells dropped below five hundred cells per microliter of blood, regardless of symptoms. It also made researchers question the usefulness of small, quick trials.⁴¹⁷

TAG extrapolated the experience with AZT to the drug development process in general. “Now we had all these questions about how to use [AZT],” said Moisés Agosto, a former member of ACT UP/New York, a member of TAG's board, and director of research and treatment advocacy for the National Minority AIDS Council at the time of our 1995 interview. “Everybody was so confused. We had advocated so much for that drug—in-

⁴¹⁷. David Brown, “Popular US Treatment for HIV is Challenged by European Study,” *Washington Post* (9 June 1993), A4.

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stead of building knowledge of pathogenesis and basic research.”⁴¹⁸

Saquinavir was the first of a new family of drugs called protease inhibitors—literally designed to inhibit an enzyme needed by HIV to infect new cells. Used in combination with AZT, ddC (Dideoxycytidine, like AZT, is a drug that disrupts the virus’s reproduction), or both, saquinavir had showed promise in a six-month clinical trial in 1994. The two hundred people with AIDS on the new drug had increases in their CD4 counts, and decreases in viral load, gauged by a more recently developed test that actually measured the amount of virus present in the blood. The higher the viral load, the greater the chances of developing AIDS-related symptoms and infections. Based on its data, Hoffmann–La Roche prepared to ask the FDA to grant it accelerated approval of saquinavir under the FDA’s two-year-old policy that allowed the agency to license drugs with minimal evidence of their effectiveness based upon the blood markers.

TAG in August 1994 urged the FDA to hold off on approving Hoffmann–La Roche’s application for accelerated approval of saquinavir. Instead, TAG called for an eighteen thousand-person long-term trial to ensure the collection of in-depth data—precisely the kind of clinical trial that ACT UP and other activists had protested only a few years before. TAG broke away not only from virtually all other treatment activists in the country, but from the FDA itself, which had granted accelerated approval in the first place because of the persistent pushing of AIDS activists.

More than fifty organizations united to urge the FDA to save the accelerated drug process they had worked so hard to get.

⁴¹⁸. Moisés Agosto, interview with author, Washington, DC, 5 September 1995.

VICTORY DEFERRED

Pharmaceutical companies that had champed at the bit under the FDA's former regulatory policies welcomed the activists' success in doing what they had been unable to do themselves. In fact, the unlikely alliance of politically conservative multinational corporations and the extreme leftists of the AIDS activist movement had been profoundly successful in reforming the FDA. Now the "TAG boys" wanted to go back to the future.

But in 1994, TAG was "behind the eight ball," said Ellen Cooper, who had moved from the FDA to the NIH Office of AIDS Research, where she oversaw the development of new drugs through NIH-sponsored clinical trials. "They came out recognizing the value and need for trials," she said. "But the field is moving ahead. That was an appropriate position four or five years before. But with viral load testing in particular, and with combination therapy, a new approach is needed to evaluate those drugs."⁴¹⁹

By monitoring the viral load and CD4 counts—generically referred to as "surrogate markers" because the increase in the former and decrease in the latter signify the progression of HIV infection—it was possible to know fairly quickly whether a given drug had any effect against HIV.

Other treatment activists were furious with TAG. "TAG breaks my heart," said Larry Kramer. "It's as if they'd never been in ACT UP at all, as if all their experiences in grass-roots activism taught them nothing."⁴²⁰ For once, Kramer's words were tame compared to the opinions of TAG expressed by others. Bill Bahlman, a charter member of ACT UP/New York who worked with the TAG founders on the Treatment and Data

⁴¹⁹. Ellen Cooper interview.

⁴²⁰. Kramer, *Reports from the holocaust* (1994 edition), 303.

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Committee, said that in opposing the accelerated access to new drugs that activists had pushed for since ACT UP's founding, TAG had betrayed the activist agenda. He noted, "If any individual outside the community—whether a pharmaceutical company, the FDA, NIH, or Congress—was pushing for the things that TAG has been pushing for, we'd be picketing their apartments at one o'clock in the morning."⁴²¹ Even John James, widely respected as a moderate voice among treatment activists, said, "We have TAG saying they want the large trials that are going to take thousands of people and years for every drug studied. Now we need small, rapid studies to find out what the best drugs are to put into the larger trials. That's not just between me and TAG, but the whole community is going in that direction."⁴²²

Even if the science had moved beyond the need for what are called large, simple trials—in this case, comparing saquinavir to a placebo—TAG's rationale was "altruism." Writing in *POZ* magazine, TAG founder Peter Staley said, "Perhaps the time has come to defer immediate hypothetical benefit—often couched in terms of right-of-access—in favor of near-term and long-term benefits for all of us. This is known as altruism. By definition it means that individuals give up some immediate benefit for the longer-term benefit of the group." Staley continued, in words that would ring hollow a few months later. "It may be harsh to frame this debate in terms of selfish individualism versus altruism or symptomatic versus asymptomatic, but demanding access for the individual without insuring a process to benefit the entire group becomes just that: A small circle of

⁴²¹. Bill Bahlman, interview with author, New York City, 3 March 1995.

⁴²². James interview.

VICTORY DEFERRED

people in the know may benefit while the majority is left with nothing. We should strive to do better.”⁴²³

Hoffmann–La Roche rejected the idea for a large trial, though it didn’t file a New Drug Application for saquinavir until August 1995. In a November hearing of the FDA’s Antiviral Drugs Advisory Committee, the drug company was asked about its incomplete research. But enough evidence had been gathered to suggest that saquinavir had at least a modest, short-term benefit. The committee recommended approval, and the FDA granted it three weeks later—a record ninety-seven days after the company applied.

TAG was there with everyone else demanding immediate access to the drug.⁴²⁴ Altruism be damned, survival was the main thing, as it had been for empowered people with AIDS throughout the epidemic. But the issues raised in the case of saquinavir, and TAG’s call for individuals to nobly consider the greater good above their own interests—presumably including their health, possibly even their lives—went well beyond the development of promising new drugs. TAG had become what Peter Staley referred to as “a small circle of people in the know.” Not coincidentally, they were overwhelmingly white, middle-class, and had private health insurance. They also had connections with scientists at the highest levels of American biomedical research. Their notions of what was right, wrong, and necessary didn’t always jibe with the realities of others with HIV who didn’t meet regularly with government officials and corporate CEOs.

⁴²³. Peter Staley, “Start Making Sense,” *POZ* (August–September 1995), 40.

⁴²⁴. Tim Horn, “Protease Inhibited,” *POZ* (April 1996), 64.

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Although he was a board member of TAG, Moisés Agosto's job with the National Minority AIDS Council kept him grounded in the reality of the lives of people of color, who comprised ever-increasing numbers of those with HIV in this country. Agosto noted that treatment advocacy had never been a major priority for people of color, for a variety of reasons including their traditional mistrust of the medical establishment, social and health burdens in addition to AIDS, and the need for political skills to insist upon a place at the table surrounded by white, male faces.

As much as anything, people of color hadn't made treatment activism a priority because they figured they were unlikely to have access to new treatments anyway. "When you have good insurance," said Agosto, "when you have a good doctor, when you have education, when you have access because you're a white man or you have money, your priorities change. You don't have to deal with all those social issues we have to take care of in communities of color. You can go right straight to the cure and treatment."⁴²⁵

For poor people of color who didn't have good insurance, education, or political access, there were other priorities. As for everyone else, survival ranked high on the list. Like the white gay men who demanded access to experimental drugs in the late eighties, poor people of color, after years of underrepresentation in clinical trials, despite the disproportionate number of AIDS cases among them, had come to see participation in clinical trials as the only way to receive medical care. But in late 1994, NIAID announced it was axing three of its four community-based trials in New York. Naturally the motive given was scientific: these particular trials simply did not meet the right research criteria. Within three years, the number of people en-

⁴²⁵. Agosto interview.

VICTORY DEFERRED

rolled in trials in New York—with more than seventy thousand AIDS cases at the time—was expected to drop from 2,130 to only 534.

NIAID's Jack Killen said at the time, "Do we have an obligation to provide everyone access to clinical trials? No, we don't. The purpose of health care is to provide health care. The purpose of clinical trials is to provide research to provide health care." He added, "Fundamentally, it's a problem of the health care system. If they could go and get treatment that is currently available we wouldn't be having this discussion."⁴²⁶

But "this discussion" had been going on since at least 1987, when AIDS activists first called attention not only to the protracted drug development process but also to the flaws in the health care system itself. Perhaps the single biggest flaw was (and still is) the fact that only those with private health insurance, linked to employment, get the best treatment. Those without it are left to fend for themselves. If their income is low enough and they can qualify as "disabled," there may be Medicaid. Or, as I myself did for the first ninety-six weeks after realizing my prescription-capped individual health insurance policy wouldn't cover even one month's worth of my HIV medications, they can try to get into a clinical trial where they can get medical care and, hopefully, effective treatment for HIV infection.

The three New York programs, which were in fact phased out, accounted for 25 percent of all African-Americans, as well as 59.5 percent of Hispanics, 38 percent of the women, and 45 percent of the intravenous drug users enrolled in NIAID's program nationally. Unlike the middle-class, gay, white men with health insurance plans that gave them access to physicians

⁴²⁶ Felicia R. Lee, "US Cuts AIDS Research Grants in New York City," *New York Times* (8 November 1994), A1.

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who were affiliated with research studies based in university hospitals, these people had no other options. Nevertheless, Gregg Gonsalves, another member of TAG, told the *New York Times* that the demands of outraged New York researchers and politicians to preserve the programs could be construed as “political pork.” As if intentionally flouting the vision of ACT UP and the arguments of AIDS activists across the country and throughout the epidemic, Gonsalves said, “We’re getting into politics. This is research. Research does not equal health care. Are we going to treat research as pork? It’s really hard.”⁴²⁷

It was even harder to understand where and why the cherished principles of AIDS advocacy had changed so drastically for treatment activists like Gonsalves and TAG. Actually, the “where” seemed to have been the meeting rooms and dinner tables in Washington where TAG worked on the “inside.” The “why” seemed to have to do with their desire to continue to be invited into those rooms and to those tables. Not only did they sound like the “junior scientists” others accused them of thinking themselves, but they seemed to have adopted the pre-AIDS mindset of the actual scientists whom activists had denounced for looking at human beings as nothing more than “subjects” and for regarding clinical trials of promising treatments as nothing more than scientific experiments.

It was the activists’ own arguments that AIDS research and care are inextricably linked which led to the expedited release of new drugs, lower drug prices, and community-based drug trials. It was their arguments that led to a shift in thinking about clinical trials as sources of care rather than only dispassionate scientific experiments. As Ellen Cooper explained, before AIDS activists argued for access to clinical trials as a “right,” such trials were seen historically as risk situations for patients. “That

⁴²⁷. Ibid.

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was the model until AIDS,” she said. “Then it became much more a right to enter trials, and the government ought to support trials so anybody who wants to get in one can—which is really a remarkable change.”⁴²⁸

For these things alone, AIDS activists could claim credit for some of the most tremendous changes in the history of American medicine. As Robert M. Wachter noted in a 1992 editorial in the *New England Journal of Medicine*, “Because AIDS activists have demonstrated the degree of influence that a well-organized, highly motivated advocacy group can have, we can be certain that the empowerment of patients will be a major part of the American social landscape of the nineties.”⁴²⁹

But with prominent AIDS activists now a part of the system they had once condemned, parroting words like “altruism” in the hope that others—certainly not themselves—would make sacrifices for the sake of medical science, the medical landscape for poor people of color with HIV seemed as bleak as ever. It’s easy to ask others to be “altruistic” when you can get immediate access to a promising new drug because of your connections. Privilege has its rewards.

What of those who had never known privilege, whose best hope for good medical care was the clinical trials they participated in—the same way it had been for white gay men in the eighties? Gay activists had once complained bitterly that the scientific establishment didn’t care about gay lives, and they refused to accept the idea that some lives might have to be

⁴²⁸. Ellen Cooper interview.

⁴²⁹. Robert M. Wachter, MD, “AIDS, Activism, and the Politics of Health,” *New England Journal of Medicine* 326 (9 January 1992): 128–32.

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sacrificed now to secure better health for later generations. Had gay lives suddenly taken on added value when a few of those leading them became a part of the establishment?

It was hard to believe the brilliant legacy of AIDS activism and PWA empowerment could devolve to a small circle of people in the know who repudiated the movement's charter beliefs, called upon others to sacrifice their personal interests for the greater good—and then were first in line to get the best treatment for themselves as soon as it became available. Of course they continued to call what they did self-empowerment. Most others called it selfishness.

No matter how highly TAG members valued their own lives, gay lobbyists in Washington regularly downplayed the impact of AIDS on the lives of gay men in this country to win political support and funding for treatment and services. Like TAG members, the “coat-and-tie” politicians thrived on working inside the federal system. Doing so, they would accomplish impressive political feats with tremendous benefits for people with AIDS. But in the process they struck bargains with the devil of a homophobic political system, and were denounced by “street” activists who, after making their own significant contributions, began to spin out of control with fits of rage they increasingly directed at gay leaders. Mud wrestling was never as dirty as what went on between the street activists and Washington lobbyists.

PART 6

ADVANCE AND RETREAT

*We'd spent so many years huddling in the ghetto
that it never occurred to us to turn to the federal government.*

EDMUND WHITE, *THE FAREWELL SYMPHONY*

AIDS has often been described as history's most "political" disease. Because it most visibly afflicted gay men at first, the combination of the morally and politically charged issues of homosexuality and death—as well as everything associated with them—ensured that the politics of AIDS would shake the nation's political system to its core. The refusal of gay people to accept the stigma society attached to AIDS—hell, they'd been stigmatized for years anyway—and their willingness to stand up to the federal and medical establishments to demand what they felt was rightfully theirs as Americans, further infused the AIDS "movement" with angry drama. How gay Americans learned, and did not learn in some cases, to focus their anger strategically is the story of a despised minority group learning to play the American game of politics. Too many times it meant accepting second-class status as the price of playing.

NINETEEN

“Unless we fight for our lives, we shall die,” wrote Larry Kramer in his 1983 article “1,112 and Counting.”⁴³⁰ Kramer described what little was known about AIDS at that point, excoriated public officials for ignoring the growing epidemic, and lambasted gay men and the gay press for their refusal to take the threat of AIDS seriously. The only praise Kramer had was for the National Gay Task Force—“our only hope for national leadership, with its new and splendid leader, Virginia Apuzzo.” And he set the stage for the kind of direct-action AIDS activism that hadn’t to that point happened anywhere.

Before “1,112 and Counting,” gay people were doing what they could to care for the sick and mourn their dead with quiet dignity. After the article’s publication, they continued to do those necessary things, but they grew increasingly unwilling to be quiet about the deaths of gay men and the preternatural silence about the epidemic from elected officials.

Kramer’s article was accompanied by a call for three thousand volunteers to join in “demonstrations of civil disobedience” that Kramer said might include sit-ins, traffic tie-ups, and arrests. The appeal for volunteers to protest was unsuccessful. Kramer said that only about fifty people showed up to “meet for instruction with a straight Black man who had worked with Martin Luther King, Jr.” The group called themselves the AIDS Network Public Events Committee. In a letter to New York May-

⁴³⁰ Larry Kramer, “1,112 and Counting,” *New York Native* (14–27 March 1983). In *Reports from the holocaust: The Making of an AIDS Activist* (New York: St. Martin’s Press, 1989), 33–51.

VICTORY DEFERRED

or Ed Koch that he wrote on behalf of the AIDS Network, Kramer said the gay community's frustration and anger at the city's inaction on AIDS "will manifest itself in a manner heretofore not associated with this community and the gay population at large." AIDS, he said—accurately, though a bit prematurely—"has, ironically, united our community in a way not heretofore thought possible."⁴³¹

Kramer's article and letter to the mayor were the last straws for GMHC's board of directors, who were angry at his outspokenness and insistence that the organization should play a more active political role. In New York, some gay leaders denounced Kramer as "sex-negative" and accused him of using AIDS "to deliver his post-*Faggots* 'I told you so.'"⁴³² But while GMHC fumed and other gay men in New York continued to downplay the growing epidemic, "1,112 and Counting" was reprinted in gay newspapers throughout the country. Kramer was just starting to have a political impact—which was ironic in view of the fact that just a month earlier he had said in the GMHC newsletter, "There is one thing we must not allow AIDS to become, and that is a *political* [Kramer's emphasis] issue among ourselves. It's not. It's a health issue for us."⁴³³

Before the AIDS epidemic, Larry Kramer was not a politically active gay man. In fact, he steered clear of gay political activism because, in his view, "All that activism was focused

⁴³¹. Larry Kramer, "The AIDS Network Letter to Mayor Koch." In *Reports from the holocaust*, 52–59.

⁴³². Randy Shilts, *And the Band Played On* (New York: St. Martin's Press, 1987), 245.

⁴³³. Larry Kramer, "Where Are We Now?" GMHC Newsletter, No. 2, February 1983. In *Reports from the holocaust*, 27.

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around sex, around the freedom to fuck wherever, whenever, however, and whomever.”⁴³⁴ His circles of friends consisted of upper-middle-class white gay men in Manhattan who spent summer weekends at Fire Island Pines and winter weekend nights in the city’s hottest dance bars, like The Saint. But Kramer’s world was rocked when those who peopled it began to get sick and die. He immediately began to use his reputation, media connections, and the gifts he had displayed as a polemicist in *Faggots* to draw attention to AIDS. Kramer’s anger at the lack of interest with which the city and federal governments—and the gay community—were handling the epidemic while his friends were dying sparked what before had only been a latent activism in himself. As he put it, “I’d been an angry kid since I was born. So it was all a marriage made in heaven.”

A year before the appearance of “1,112 and Counting,” the Centers for Disease Control reported in March 1982 that 285 cases of what was being called Gay Related Immune Deficiency (GRID) had been diagnosed in seventeen states. Half the cases were in New York and a quarter were in California.⁴³⁵ In San Francisco that month, the gay Stonewall Democratic Club sponsored the city’s first forum on the new disease, calling it “Gay Cancer.” Bobbi Campbell, the sixteenth person in San Francisco to have been diagnosed with Kaposi’s sarcoma, and the self-proclaimed “K.S. Poster Boy,” came to show the group what the unusual skin cancer looked like. Twelve people showed up.

The other gay political groups were preoccupied with trying to line up delegates to the Democratic National Convention,

⁴³⁴. Larry Kramer, interview with author, New York City, 4 March 1995.

⁴³⁵. Shilts, *And the Band Played On*, 131.

VICTORY DEFERRED

which would be held in San Francisco in 1984. After the forum, the Stonewall club also moved on to the more pressing business of organizing a gay rights march to be held during the Democratic convention. As the gay political groups prepared for the convention, San Franciscans were taken aback by a “Startling Finding on Gay Disease,” reported by Randy Shilts in the *San Francisco Chronicle*: One out of every 350 gay men in the city was believed to be suffering from AIDS.⁴³⁶

A hundred thousand people showed up for the National March for Lesbian and Gay Rights on July 14, 1984, in a distinctly San Franciscan version of Bastille Day. On the eve of the march, the Sisters of Perpetual Indulgence staged a mock exorcism of a woman dressed as archconservative Phyllis Schlafly and ripped off the pants of a Reverend Jerry Falwell look-alike to expose fishnet stockings and a black corset.⁴³⁷ Both Schlafly and Falwell were in San Francisco at the time, rallying their own anti-gay forces.

The momentum generated by the July march spiraled into support for an independent gay AIDS activist group in San Francisco. Other gay community leaders tapped thirty-one-year-old Paul Boneberg, then president of the Stonewall Democratic Club, to lead the new group. Mobilization Against AIDS came into existence in the fall of 1984 with the express goal of organizing street demonstrations, a goal it accomplished by staging monthly protests. Besides its street demos, Mobilization, beginning in 1985, took on the task of organizing

⁴³⁶. James Kinsella, *Covering the Plague: AIDS and the American Media* (New Brunswick, NJ: Rutgers University Press, 1989), 262, 263.

⁴³⁷. Shilts, *And the Band Played On*, 467.

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the annual AIDS candlelight vigil that the San Francisco PWA Coalition had started two years earlier.

Another San Francisco group, Citizens for Medical Justice, began in early 1985 to do nonviolent civil disobedience. The group constructed their “AIDS Vigil,” an encampment of a half-dozen tents that the *New York Times* said “stood as a silent, if unsightly reproach to indifference” on the grounds of the old Federal Building in the civic center until hundred-mile-an-hour winds flattened them in December 1995.⁴³⁸

Shortly after the candlelight vigil in May 1985, Mobilization sponsored the first PWA lobbying day in Washington, D.C. Michael Callen was there, issuing a challenge to President Reagan, who still had not spoken publicly about AIDS, “Say the word ‘AIDS,’ Mr. President!” The lobbyists also attacked friends in Congress, such as California Representative (now Senator) Barbara Boxer, demanding that Congress hold hearings on AIDS in San Francisco. Boneberg explained, “There was a definite influence in the strategy by the old Vietnam war organizers, who said the Vietnam war was ended when you attacked moderate Democrats, and therefore what we have to do is, in effect, attack our friends to move forward.”⁴³⁹

Meanwhile, in New York, a group of gay activists with roots in the gay liberation movement of the early seventies formed the Swift and Terrible Retribution Committee. The reaction by gay people was indeed swift after William F. Buckley, Jr. published an article in March 1986 claiming, “it is both a fact and

⁴³⁸. Michael J. Ybarra, “Nature and Apathy Destroy AIDS Vigil,” *New York Times* (22 December 1995), A22.

⁴³⁹. Paul Boneberg, interview with author, Washington, D.C., 17 August 1995.

VICTORY DEFERRED

the popular perception that AIDS is the special curse of the homosexual” (despite epidemiological figures at the time showing that worldwide AIDS was afflicting far more heterosexuals), and called for the tattooing of gay men with AIDS on the rear end and drug users on the arm.

The Retribution Committee swung into action, protesting—in concentration camp uniforms—at the Manhattan headquarters of Buckley’s *National Review*. That summer, the group struck again, this time picketing a visit to New York by Supreme Court Justice Warren Burger, not long after the Supreme Court handed down its ruling in the *Bowers v. Hardwick* sodomy case. The hometown of Broadway wouldn’t let San Francisco outdo it in the street theater department, and a group calling themselves the “New Supremes” serenaded the twenty-five hundred protestors with their version of “Stop that kind of love, before you break the law.”

About a dozen people from the Swift and Terrible Retribution Committee began to meet at the apartment of Bill Bahlman, in the West Village, planning the kind of “zaps” that gay activists had used in the years immediately following the 1969 Stonewall riot. Calling itself the Lavender Hill Mob, the breakaway group began in late 1986 to direct its attention at targets like the Catholic Church and the *New York Times*. The mob surfaced nationally at a March 1987 conference sponsored by the CDC, in Atlanta, to discuss mandatory HIV antibody testing. Bahlman recalled venting his own anger at the gay community leaders at the meeting, letting loose during a press conference they held after the participants in the meeting voted against mandatory testing.

Bahlman said the activists were “congratulating themselves” on the adoption by conferees of a position opposing mandatory testing. Bahlman shouted at them, “Where is your anger?”

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PWAs are dying! Our community is being decimated, and here you are patting yourselves on the back for what was a foregone conclusion—no one was for mandatory testing at this conference. And here you are speaking in front of the press as if we had some major victory—and we’re all dying.”⁴⁴⁰

The Mob’s next national appearance was at the Third International AIDS Conference, in Washington, D.C., the first week of June 1987. The protestors marched outside the Washington Hilton, where President Reagan had been shot in 1981, chanting, “We’re dying of red tape”—a reference to the interminable federal drug approval process. One of the banners the protestors held up said, “Hey Mr. President. Just Say Yes to More: AIDS Funding, Education, Research, Drugs, Safe Sex, Anonymous Testing.” Another slogan that would become internationally famous also made its global debut that day: “Silence = Death.”

The boos that had greeted President Reagan’s first-ever speech on AIDS the night before were echoed that Monday, June 1, when Vice President George H. W. Bush endorsed the president’s call for mandatory testing in a speech to the assembled scientists. Returning to his seat afterward and thinking he was off-mike, Bush asked Assistant Secretary for Health Robert Windom, “Who was that, some gay group?”⁴⁴¹

Bahlman recalled the boos that had provoked Bush’s gaffe: “Of course it was Henry [Yaeger], Martin [Robinson], and myself.” The anger that Bush elicited that morning spilled over at

⁴⁴⁰. Bill Bahlman, interview with author, New York City, 3 March 1995.

⁴⁴¹. John-Manuel Andriote, “AIDSweek: May 31–June 5,” *Washington City Paper* (June 12, 1987), 6–11.

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noon in a planned civil disobedience demonstration at the White House. About 350 people gathered in Lafayette Square, across from the White House, to protest a lack of funding for AIDS research and the snail's pace of federal AIDS education programs. "Reagan, Reagan, too little, too late," they chanted. Led by former Legal Services Corporation head Dan Bradley, who had AIDS at the time, a group of sixty-three protesters stepped over a concrete barrier onto Pennsylvania Avenue and blocked traffic by sitting on the street. Wearing riot helmets and bright yellow rubber gloves, DC police escorted the protesters—among them, Dan Bradley, Larry Kramer, Larry Mass, and Ginny Apuzzo—to waiting police buses where they were photographed and handcuffed.⁴⁴²

Vivian Shapiro, then the national co-chair of the Human Rights Campaign Fund (HRCF, now HRC), a gay lobbying organization in Washington formed in 1983, said of her arrest, "Truly, being arrested was the only action I knew to begin to release my frustration at the insanity of this [Reagan] administration. It was a primal scream."⁴⁴³ The photographs of prominent gay leaders being arrested ran in newspapers across the country, and the nation was given its first taste of a new kind of AIDS activism.

It was called ACT UP.

"The fact that everybody responded to ACT UP, I think was more just a question of time, and moment, and frustration," said

⁴⁴². Bahlman interview.

⁴⁴³. Paul Akio Kawata, ed., *Americans Who Care: Volunteers Working in the Battle Against AIDS* (Washington, DC: National AIDS Network, 1987), 77.

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Larry Kramer. “It was the right time for it to happen.”⁴⁴⁴ In a speech at the New York Gay and Lesbian Community Center on the night of Tuesday, March 10, 1987, Kramer laid into the gay community in the way that only Larry Kramer could: “I sometimes think we have a death wish,” he railed. “I think we must want to die. I have never been able to understand why for six long years we have sat back and let ourselves literally be knocked off man by man—without fighting back. I have heard of denial, but this is more than denial; it *is* a death wish.” The crux of the speech was Kramer’s simple question: “Do we want to start a new organization devoted solely to political action?”⁴⁴⁵

Two days later, about three hundred people again showed up at the center. They answered Kramer’s question with the formation of ACT UP, the AIDS Coalition to Unleash Power, a leaderless protest group, “democratic to the point of near anarchy.”⁴⁴⁶ Bill Bahlman and other veterans of the Lavender Hill Mob, just back from the CDC conference in Atlanta, provided training to the seventy-five people who formed the initial core of ACT UP. Marty Robinson taught ACT UP how to negotiate with the police. Henry Yaeger taught people how to wheat-paste notices about upcoming actions on streetlights. Jean Elizabeth Glass taught them how to train marshals for demonstrations. Bahlman himself provided instruction on writing flyers and dealing with the medical research establishment.⁴⁴⁷

⁴⁴⁴. Kramer interview.

⁴⁴⁵. Larry Kramer, “The Beginning of ACTing Up/1987.” In *Reports from the holocaust*, 128, 135.

⁴⁴⁶. David B. Feinberg, *Queer and Loathing: Rants and Raves of a Raging AIDS Clone* (New York: Penguin Books, 1994), 10.

⁴⁴⁷. Bahlman interview.

VICTORY DEFERRED

These early members of ACT UP may have needed training in the finer points of civil disobedience, but they were more than eager students. For them this was hardly an academic exercise. Bahlman explained, “This wasn’t something where they said, ‘Someone should do something about AIDS, and I guess I should do something.’ These were people who had lost their lovers, who had lovers who were sick, who had AIDS themselves.”⁴⁴⁸

ACT UP’s first demonstration—a protest on Wall Street against the exorbitant price of just-approved AZT—introduced what became the group’s distinctive brand of street theater. Older activists were gratified to see a return of the colorful demos and zaps they had pioneered in the early seventies. But the rage! The rage was more than anger at the suffocation and second-class citizenship of the closet. These gay people were outraged that they weren’t getting the treatment they expected as taxpaying Americans. They were furious about the neglect they were experiencing from the government because of a sexual orientation and now a disease that rendered them expendable—just like the nation’s poor, who suffered the same fate.

As with other AIDS organizations that were started by middle- and upper-middle-class gay white men, the angry energy that drove ACT UP came at least in part from a sense of betrayed entitlement, a feeling that they weren’t getting their due. Allan Robinson, a Black gay man active in ACT UP, said, “One of the things I picked up, especially among the upper middle class, is that they were goddamned angry. They were angry because they thought they had everything—trips to Brazil, and Fire Island, hanging in the clubs, boyfriends, drugs, money, and living perhaps on Eighty-First Street and Central Park West.

⁴⁴⁸. Ibid.

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They were angry because they were being treated like everybody else.”⁴⁴⁹

Two months before President Reagan would finally utter the word “AIDS”—six years into the epidemic—the group asked, “Who is in charge?” The demonstration and arrests made national news. And when FDA Commissioner Frank Young announced several weeks later that the FDA was speeding up its drug approval process, CBS anchor Dan Rather credited ACT UP’s pressure.⁴⁵⁰

The energy and early successes of ACT UP sparked the formation of ACT UP chapters in cities throughout the United States and in several other countries as well. In San Francisco, for example, activist Hank Wilson recalled, “We formed ACT UP here because we liked the name, we got off on the energy of the people in New York, and we loved their graphics.”⁴⁵¹ In Atlanta, Jeff Graham, later director of the city’s AIDS Survival Project, joined the local ACT UP chapter because he saw it as

⁴⁴⁹. B. Michael Hunter, “Allan Robinson, AIDS Activist.” In B. Michael Hunter, ed., *Sojourner: Black Gay Voices in the Age of AIDS* (New York: Other Countries Press, 1993), 54–61.

⁴⁵⁰. Douglas Crimp and Adam Rolston, *AIDS DemoGraphics* (Seattle: Bay Press, 1990), 26–30. Note: Crimp and Rolston say this first ACT UP demonstration took place on Thursday, 24 March 1987; however, 24 March 1987 was a Tuesday—exactly two weeks after Larry Kramer’s 10 March speech at the Gay and Lesbian Community Center, in New York, which is credited as having launched ACT UP.

⁴⁵¹. Hank Wilson, interview with author, San Francisco, 30 January 1995.

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the only group with “the enthusiasm, commitment, and energy” he wanted.⁴⁵²

ACT UP members were predominantly gay, and the group’s sensibility often drew deeply from gay camp humor. In 1989, for instance, it launched a campaign against New York Health Commissioner Stephen Joseph, called “Surrender Dorothy!,” a title taken from *The Wizard of Oz*, the 1939 film that launched the career of Judy Garland, an icon of many gay men. In the years before the Stonewall uprising, gay men often referred to themselves as “friends of Dorothy.” Familiarity with the expression conveyed to another man that one was gay. Strangely, yet shrewdly, ACT UP downplayed its gay identity, insisting it be known only as an AIDS activist organization. ACT UP/New York member Michael Petrelis claimed in a letter to the editor in the *Wall Street Journal* that “ACT UP isn’t ‘gay’” because the group welcomed heterosexuals and anyone else interested in stopping AIDS.⁴⁵³

ACT UP’s real moment in the sun—actually the spotlight of media coverage—was its October 11, 1988, protest against the FDA. A year to the day after the second March on Washington for Lesbian and Gay Rights, and just after the second showing of the AIDS Memorial Quilt in Washington, DC, “Seize Control of the FDA” was the most widely publicized of ACT UP’s early

⁴⁵². Jeff Graham, telephone interview with author, 13 September 1995.

⁴⁵³. Michael Petrelis, “ACT UP Isn’t ‘Gay,’” *Wall Street Journal* (21 February 1992), A-15.

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demonstrations.⁴⁵⁴ The demonstration was organized by ACT NOW—a network of ACT UP chapters throughout the country that had formed during the 1987 march, primarily to protest the FDA’s hidebound procedures for the testing and approval of new drugs.

Michelangelo Signorile, who oversaw the media coverage of the demonstration as head of ACT UP/New York’s media committee, recalled, “What we had done was organized a well-rehearsed circus. What we were doing was exploiting each other in order to get the message across.” As a former gossip columnist, Signorile said, “I dealt in sleaze and dirt and I spoke the language of the masses.”⁴⁵⁵ All of Signorile’s skills were put to use on behalf of the FDA action, as ACT UP’s medical committee began months in advance to promote the event to the media throughout the country, distributing more than five hundred press kits that included what he described as a “really hokey, tear-jerking cover letter.”

ACT UP was assisted in promoting the demonstration—touting it as “the largest act of civil disobedience since the storming of the Pentagon over twenty years ago”—by Urvashi Vaid, then the media coordinator for the National Gay and Lesbian Task

⁴⁵⁴. Crimp and Rolston, *AIDS DemoGraphics* (p. 76) call the FDA action “the most significant demonstration of the AIDS activist movement’s first two years” without regard to the fact that AIDS activism, as I have demonstrated in this chapter, had been underway, particularly in New York and San Francisco, for at least the previous five years. As I note further in the chapter, this solipsism would prove to be one of ACT UP’s fatal flaws.

⁴⁵⁵. Michelangelo Signorile, *Queer in America: Sex, the Media, and the Closets of Power* (New York: Anchor Books, 1993), 4, 5.

VICTORY DEFERRED

Force (NGLTF), in Washington, DC Signorile said, “She seemed to know everyone at the networks and newspapers, and almost every reporter seemed to know ‘Urv.’”⁴⁵⁶ A veteran gay organizer and press spokesperson, Vaid put together a press conference to be held during the demonstration, and provided reporters from across the country with activist “spokespeople” from their own towns and cities.

Activists in T-shirts that said “We Die, They Do Nothing!” plastered the front of the Parklawn Building, the suburban Washington FDA headquarters, with ACT UP graphics and banners that said things like “Time isn’t the only thing the FDA is killing” and “The Government has blood on its hands. One AIDS death every half hour.” Others provided a nonstop theatrical spectacle for television cameras that ate it up. One group did “die-ins,” lying on the ground in front of cardboard tombstones with “epitaphs” such as “R.I.P. Murdered by the FDA.” Another group wrapped themselves in red tape. For Signorile, the spectacle was exactly what ACT UP had intended. As he put it, “This was going to be a spectacular demo, and a wonderful show for the media. ACT UP *always* delivered.” But “It wasn’t all show biz,” he added. “We were angry.”⁴⁵⁷

The ten-hour demonstration more or less shut down the FDA and resulted in 176 arrests. ACT UP was intoxicated with a sense of its own power. America certainly found out about ACT UP as the group lunged onto the front pages of the nation’s newspapers and into the living rooms of millions of Americans in lead stories on the TV evening news. Signorile said, “Suddenly every street activist was a ‘press whore,’ and all of us were speaking in sound bites. In-your-face activism took

⁴⁵⁶. Ibid., 10.

⁴⁵⁷. Ibid., 12.

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shape nationally, and being out of the closet in the media became the ideal for a new generation.”⁴⁵⁸

On October 24, nearly two weeks after the ACT UP demonstration at the FDA, Commissioner Young called for researchers to help speed the process for developing and approving new AIDS drugs. On the twenty-eighth, President Reagan signed a bill making October—of course the month was just ending—AIDS awareness month. And on November 8, George H.W. Bush was elected the forty-first president of the United States, calling for a “kinder, gentler nation.” Bush and many others in the federal government—as well as the “coat-and-tie” gay and lesbian lobbyists in Washington—would soon learn: Kind and gentle would not be on anyone’s list of adjectives for describing the attacks that ACT UP made in the coming years.

⁴⁵⁸. Ibid., 16.

TWENTY

“It had all the right trappings,” recalled Tim Westmoreland. “Real people, scientists, policy-makers, people from the CDC and NIH—Marcus Conant was there.”⁴⁵⁹ But the first congressional hearing on what was then called Gay Related Immune Deficiency (GRID) on April 13, 1982, could be described as the silence heard round the world if you were talking about the media coverage it did not attract. Westmoreland, then chief counsel to the House Subcommittee on Health and the Environment, organized the one-day hearing at the Gay and Lesbian Community Services Center, in the heart of sub-committee chair Representative Henry Waxman’s district in Los Angeles. Waxman functioned as a one-man subcommittee at the hearing, other members apparently preoccupied back in Washington with more important business than what in a year would be deemed the “nation’s number one health priority.”

To open the hearing, Westmoreland wrote a statement for his boss that underscored the congressman’s disdain for the Reagan administration’s creeping response to the growing epidemic, and what he thought were the reasons for it. “This horrible disease afflicts members of one of the nation’s most stigmatized and discriminated against minorities,” said Waxman. “The victims are not typical Main Street Americans. They are gays, mainly from New York, Los Angeles, and San Francisco. There is no doubt in my mind that, if the same disease had appeared among Americans of Norwegian descent, or among tennis players, rather than gay males, the responses of both the gov-

⁴⁵⁹. Timothy Westmoreland, interview with author, Washington, DC, 18 July 1995.

VICTORY DEFERRED

ernment and the medical community would have been different.”⁴⁶⁰

The symbolism of holding the first congressional hearing on AIDS at the gay community center would not be lost on anyone, least of all members of Congress, in the coming years. In fact, Congress’s response to AIDS would become intimately connected with how much power—which in Washington means the ability to influence public opinion, contribute money to political campaigns, and, above all, to deliver votes—members thought the gay community possessed and could wield. In those early days, though, neither Congress nor anyone else in Washington was paying much attention to the epidemic because there weren’t yet gay people insisting they pay attention and do something as minimal as increasing the government’s funding for research into the mysterious new disease.

Before the AIDS epidemic, gay people had no experience in Washington dealing with federal budgets and appropriations, and certainly not with the Department of Health and Human Services (HHS). The only gay presence in Washington was Steve Endean’s Gay Rights National lobby and the National Gay Task Force’s efforts to push the federal gay and lesbian civil rights bill, a revision of the 1964 Civil Rights Act, introduced by the late Bella Abzug in 1975.⁴⁶¹

Ginny Apuzzo, who became the executive director of the National Gay Task Force (NGTF; the word lesbian would be added to the name later) in 1982, said, “What you have to un-

⁴⁶⁰. Shilts, *And the Band Played On*, 143.

⁴⁶¹. Urvashi Vaid, *Virtual Equality: The Mainstreaming of Gay and Lesbian Liberation* (New York: Anchor Books/Doubleday, 1995), 7.

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derstand was that the gay and lesbian community in 1980–81 had only one experience with lobbying—that was how to get the gay rights bill through. Every session you’d go in and add two or three sponsors, get people to write from home. That’s where this community’s experience was, and it had to turn around on a dime.”⁴⁶²

Apuzzo attributed the gay leaders’ political education to Westmoreland and some of the staff of the late Representative Ted Weiss, one of whom was Patsy Fleming, President Clinton’s second AIDS “czar.” In the early years of the epidemic, Westmoreland spent a great deal of time on the telephone with gay community leaders who were running the country’s fledgling AIDS organizations. They were learning about politics in the same way they had to learn about caring for dying young men: by doing it of necessity.

Westmoreland suggested ways they might get involved in the political system. “Many,” he said, “were totally unaware of how government worked.” He provided political “tutorials” for GMHC cofounder and *Advocate* writer Nathan Fain. He also worked with another of GMHC’s cofounders. He told me, “I spent lots and lots of time on the phone—*lots* of time—with Larry Kramer, helping him understand the Public Health Service and the budget process.”

At first, said Westmoreland, gay organizations didn’t want to take on a major public health issue like AIDS. They had their hands full—that is, the very few hands there were in the professional gay civil rights movement at that point—trying to deal with discrimination issues and getting a few more supporters for the federal gay rights bill. But there was a collective epiphany.

⁴⁶². Virginia Apuzzo, telephone interview with author, 8 August 1995.

VICTORY DEFERRED

Said Westmoreland, “They came around quickly to the realization that this was threatening to undermine progress they might make in any other area.”⁴⁶³

Jeff Levi, who became NGTF’s Washington director in 1983, said that not only did gay people have to learn about Washington politics, but they had to make a major shift in their thinking about the role of the federal government as well. “The traditional gay and lesbian agenda,” explained Levi, “is ‘Stay out of our lives. It’s a privacy issue. Let us live. Let us be who we are.’ The antidiscrimination protection we were seeking is a more involved way of saying the same things.” When AIDS appeared, gay leaders suddenly realized how essential the government’s involvement—particularly its financial resources—would be to deal with a crisis of such magnitude. Said Levi, “Now we’re saying we need affirmative programs that will save our lives, not get out of our lives, and that we need a much closer relationship with the government.”⁴⁶⁴ You can be sure Ginny Apuzzo is being as diplomatic as her many years in politics taught her to be when she said, “Getting people to change their perspective was like trying to turn a ship around.”

For many gay people, especially those whose financial wherewithal provided a cushion against antigay discrimination in areas like employment and housing, AIDS brought the shocking realization that they were at risk and that their government didn’t seem to give a damn. Kramer’s article “1,112 and Counting” was a revelation for politically apathetic gay people, and those who—like Kramer himself before the epidemic—thought gay community politics were either irrelevant or beneath them.

⁴⁶³. Westmoreland interview.

⁴⁶⁴. Jeffrey Levi, interview with author, Washington, DC, 24 February 1995.

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Slowly but surely, the grass roots began to sprout around the country as gay people mobilized themselves into action. And in Washington, the gay community's few spokespeople at the time learned their own lessons—under duress and under the circumstances—very well.

By the time Apuzzo testified at a congressional hearing on August 1, 1983, the former Catholic nun would bring all her sources of strength to bear on the federal government. In an interview nearly twelve years to the day after that hearing, Apuzzo said, simply, "I demanded \$100 million for AIDS." Total federal spending for AIDS at the time was only \$14.5 million.⁴⁶⁵ Apuzzo went beyond merely asking for more funding. She ticked off the "failures" of the federal government's response to AIDS—about which she made it clear that her constituents were very angry. They included the failure to expedite funding for AIDS research, the failure to educate the public to stem hysteria about AIDS, the failure to address specific questions about the safety of the blood supply, the failure to include affected groups in decision-making, and the failure to recognize a right to confidentiality and privacy.⁴⁶⁶

Besides sharpening their skills in lobbying Congress, gay politicians in Washington cultivated relationships with people inside the executive branch agencies, particularly at HHS. Apuzzo recalled that when she first met Ed Brandt, number two in Reagan's HHS, "he looked at me like I'd lost my mind." But

⁴⁶⁵. Shilts, *And the Band Played On*, 359.

⁴⁶⁶. Apuzzo read this list of failures from a press release issued by the National Gay Task Force on 1 August 1983, the day of the hearings sponsored by New York Representative Ted Weiss's Government Operations Subcommittee on Intergovernmental Relations and Human Resources.

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Apuzzo wouldn't leave the conservative Oklahoma Republican doctor alone. "I kept working on him," she said, "giving him data, giving him facts."

Brandt eventually came to support Apuzzo's efforts, even if he had to do so on the sly to avoid being caught by other hawk-eyed Republicans. Apuzzo remembered that after Brandt sent what was supposed to be a confidential memo to HHS Secretary Margaret Heckler, in 1984, asking for \$55 million more than the administration's \$51 million request for AIDS, "it ended up in our mailbox in a plain brown envelope." Tim Westmoreland leaked a copy of the same memo, which he'd also received in a brown envelope, to the *Washington Blade*, the DC gay community newspaper, where a story about it ran on page 1.⁴⁶⁷

Not only did Brandt furtively send copies of his memos to key players on the Hill and in the gay organizations that had come to embrace AIDS as a political issue, but he seemed to have learned to appreciate the humanity and decency that people like Ginny Apuzzo, Jeff Levi, and Tim Westmoreland brought to their political work. After his leaked memo had become what Randy Shilts called "the watershed event in the AIDS budget battle of 1984,"⁴⁶⁸ Brandt announced his resignation from HHS. Before he left, though, he spent his last day with Apuzzo, and later sent her a handwritten letter saying he wished he'd spent more time with her.

Gay politics was coming of age in the nation's capital. But before anything significant could be accomplished, it would take some odd twists and turns and even camouflage itself for protection against hostile politicians.

⁴⁶⁷. Shilts, *And the Band Played On*, 466–67.

⁴⁶⁸. *Ibid.*, 466.

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After eight years in the Middle East with the Foreign Service, Gary MacDonald was glad to be back in the States, and ready for a job in which he could feel more comfortable about being gay. Jeff Levi told MacDonald about a job opening with a new group called the Federation of AIDS Related Organizations (FARO). FARO was formed by thirty-eight community-based AIDS organizations at the June 1983 Second National AIDS Forum, in Denver, to provide members with a means to network with one another. The group also wanted a presence in Washington, and in August 1983 hired a health lobbyist to singly man their “lobby project,” which they called the FARO AIDS Action Council. MacDonald was interviewed at Whitman-Walker Clinic, then a tiny operation in D.C.’s Adams-Morgan neighborhood. GMHC’s board president, Paul Popham, came down from New York to scope out MacDonald on FARO’s behalf. He gave the nod, and MacDonald was hired to be the first executive director of what today is simply called AIDS Action.

MacDonald’s job was to lobby Congress and the administration to increase funding for AIDS research and education. It was “extremely lonely,” he told me, looking back at those early years when he was literally the only person in Washington working full time on AIDS political issues. Working out of the second bedroom of his Capitol Hill apartment, MacDonald and the fledgling AIDS Action Council faced daunting odds against the success of their mission. As MacDonald put it, “There was no AIDS industry, no public consciousness, no fundraising, no prevention—in short, nothing.”

Within a year and a half after MacDonald started his new job in 1984, the virus that causes AIDS was discovered, an antibody test became available, and Rock Hudson died. “The barometer shot way up,” he said, and the telephone at AIDS

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Action Council—like that early hotline in San Francisco that Cleve Jones recalled—now “rang incessantly.”

A lot of MacDonald’s time in those early years was spent educating people in the government about homosexuals. Because of his willingness to be open about being gay, MacDonald was invited to join the government’s early advisory panels on counseling and testing, prevention education, and, as he said, “really in some sense on the gay community.” He explained, “There was enormous ignorance in the early days: ‘Who are these people? How many of you are there? Where do you live?’ I’d get calls from people at CDC asking, ‘What percentage of the population is gay male?’ They were doing all this projecting and numbers and statistical models trying to figure out just how bad this really was.”⁴⁶⁹

Despite the perception of policy-makers and everyone else in Washington that AIDS Action Council was a gay organization that represented a group of gay-run AIDS organizations, MacDonald said, “The council had deliberately decided not to position itself as a gay organization. That was a board decision, which I supported.” While AIDS Action represented organizations that derived from the gay community, the council itself never saw itself as a gay organization—just like ACT UP. Said MacDonald, “I think it helped to establish the fact that this disease does not just strike gay men, it’s not just a gay disease—which was at that point, and still is, a common perspective.”⁴⁷⁰ A board of directors who took a laissez-faire approach to the fledgling AIDS Action Council—mostly because, as MacDonald put it, “the board didn’t know diddly about Washington”—al-

⁴⁶⁹. Gary MacDonald, interview with author, Washington, DC, 7 February 1995.

⁴⁷⁰. MacDonald interview.

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lowed the executive director to mold the organization and its image as he deemed fitting and necessary to the business of doing politics in Washington.

There were gay organizations—including D.C.’s own Whitman-Walker Clinic and Chicago’s Howard Brown Memorial Clinic—that resisted joining AIDS Action Council. “They never believed it was an important priority,” said MacDonald, ever the diplomat as he resisted adding that of course the groups likewise didn’t refuse any federal money that came their way because of AIDS Action Council’s lobbying efforts. Because membership dues for AIDS Action Council were proportional to the size of the annual budgets of member agencies, the larger, wealthier agencies kicked in considerably more money to the council’s war chest than their smaller counterparts. When Paula Van Ness was director of AIDS Project Los Angeles, the group contributed \$60-70,000 a year. The San Francisco AIDS Foundation was good for another \$70,000 a year.⁴⁷¹ And GMHC, the “world’s oldest and largest” AIDS organization, as it touted itself, was pumping \$275,000 a year into AIDS Action Council.⁴⁷²

Other AIDS lobbyists—virtually all of them gay—began to appear on the Washington scene in the late eighties. Besides contributing to AIDS Action Council, large agencies like GMHC, APLA, the San Francisco AIDS Foundation, and Seattle’s Northwest AIDS Foundation (today known as Lifelong AIDS Alliance) created policy departments and hired lobbyists to look out for their particular interests. Paula Van Ness hired APLA’s first policy director in 1985.

⁴⁷¹. Pat Christen, telephone interview with author, 20 September 1995.

⁴⁷². Timothy Sweeney, interview with author, New York City, 2 March 1995.

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In 1987, Tim Sweeney had recently left his job as director of Lambda Legal Defense and Education Fund (today known as Lambda Legal), when GMHC director Richard Dunne took him to lunch. GMHC needed to “get more political,” said Dunne—of course Larry Kramer had been saying exactly that for years—and he wanted Sweeney to come aboard and form a policy department.

As AIDS organizations were formed by and for people of color in the late eighties and early nineties, AIDS Action Council was buffeted by charges of being elitist, racist, and beholden to the white gay men who originally had formed it. Dan Bross, who was director of the council from September 1990 until November 1994, told me that he responded to such charges against the council by saying, “People with AIDS deserve better than charges of racism.” He added, “The easy part of my job at AIDS Action Council was dealing with Capitol Hill and the administration. The difficult part was dealing with the diversity of the epidemic, of the AIDS community, because people’s first reaction is to blame and to personalize and to divide, and that really is not healthy.”⁴⁷³

AIDS Action Council’s struggle to articulate its identity was the same as with every other AIDS organization originally formed by white gay men in the early eighties: Are we a gay organization? Are we an AIDS organization? What’s the difference? And what does being one or the other mean, exactly? Finding the answers—there wasn’t only one, and there definitely were not easy ones—to these questions continued in the late nineties to vex everyone involved. When I asked Bross how AIDS Action Council answered these questions during his ten-

⁴⁷³. Daniel Bross, interview with author, Washington, DC, 17 February 1995.

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ure as the group's leader, he recalled his years at GMHC that revealed a nostalgia for an earlier, easier time when most people with AIDS were gay white men and AIDS groups had a clearer sense of their identity as gay community organizations.

Unlike in the early years, when most people with AIDS were gay men, Bross noted that as the people affected changed, "the circle has changed." Now there were some gay white men, some injection drug users, some women, and a lot of people of color. "The only thing they share is they're all living with HIV," said Bross. He added that the loss of a feeling of community—from the years when the epidemic was more homogeneously homosexual—is "tearing some of these AIDS organizations apart."

AIDS Action Council's job of speaking on behalf of the AIDS "community" became complicated by the inability of that community to agree on exactly who its members were, and who should speak on their behalf. Which of course made it nearly impossible to speak with one voice to the Feds whose bureaucratic minds naturally resist ambiguity in any form.

Fortunately, in the late eighties, before the intracommunity discord became the kind of civil war it did in the mid-nineties, the council spearheaded a political coalition that was effective, powerful, and accomplished tremendously important feats in Washington that benefit people with AIDS in this country to this day. Unfortunately, the strategy it used to win support and funding for AIDS would wind up alienating many gay people who were already tired of feeling scolded, slighted, and generally viewed as second-class Americans. In a city whose residents are practically required to learn a new language consisting entirely of acronyms, the coalition was known as NORA, National Organizations Responding to AIDS.

TWENTY-ONE

AIDS Action Council's board members were very interested in Jean McGuire's two children when they interviewed her in early 1988 for the position of executive director. Although she was at that point identifying herself privately as bisexual, no one in the interview process asked directly about her sexual orientation. In a follow-up phone call from one board member, though, McGuire recalled that the individual "was trying to impress on me how important they felt it was not to have a gay image of AIDS Action Council. And a woman with two kids who was committed to this issue despite the fact that so many people affected by it are gay." McGuire told me, "I stopped the conversation and said, 'What about having two kids makes you think I'm straight?'"⁴⁷⁴

The day I interviewed McGuire in Cambridge, Massachusetts, where she was pursuing doctoral studies, happened to be the tenth anniversary of Rock Hudson's public announcement that he had AIDS. The timing of McGuire's remarks about the desire of AIDS Action Council not to be seen as a gay organization couldn't have been more appropriate. It was in fact Hudson's July 25, 1985, announcement—and the public fear and attention it brought to AIDS because Hudson was perceived publicly as a heterosexual man—that provided gay AIDS activists with a strategy they hoped would finally increase the political and financial commitment from Washington that had been in short supply since the beginning of the epidemic. They reasoned that this would happen if they played

⁴⁷⁴. Jean McGuire, interview with author, Cambridge, Mass., 25 July 1995.

VICTORY DEFERRED

down the fact that the vast majority of AIDS cases in the country at that point were among gay men, and instead emphasized that, as a *Life* magazine cover story put it, “Now No One is Safe From AIDS.”

“De-gaying” the epidemic, and playing upon the fears of heterosexuals that they also were at high risk, became the main strategy of gay AIDS advocates, including AIDS Action Council. So when a woman they perceived as heterosexual simply because she had children—she was living with a female partner at the time of our interview—wanted to be their executive director, they were elated at the prospect of being able to tell politicians, “See, it’s really not a gay disease, as this ‘straight’ woman’s involvement proves.”

The de-gaying strategy was necessary, according to Vic Basile, director of HRCF from June 1983 until June 1989, who jokingly referred to himself as “something of a political whore” in our interview. For him, playing down the overwhelming number of gay men affected by AIDS, and playing up for politicians the relatively few American women and children with AIDS at the time, was merely a political move to win sympathy and support from antigay politicians. Brooking no disagreement, Basile said, “To the extent that gay people are offended by that, the hell with them. It’s stupid not to use your most effective weapons here.”

For Basile, the “moral imperative” of AIDS politics was “to find a cure for AIDS ... not to see any more of my friends die.” Basile, with that laudable goal in mind, saw the strategy for attaining it as simply “by whatever means necessary.” Pragmatism, what is achievable, mattered above all else. As Basile put it, “If it takes Mary Fisher [white, wealthy, and heterosexual] to speak at the Republican National Convention [as she did in 1992], let’s have Mary Fisher talk about it. She’s a charismatic speaker, she’s rich, she’s mainstream—she’s all the things that

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break down those stereotypes” about people with AIDS being only gay men and injection drug users.

Basile said anyone who disagrees with this strategy is “egotistical, self-centered, and selfish” for not realizing that the ends (more funding and ultimately a cure for AIDS) justify the means (soft-pedaling the fact that the majority of people with AIDS in the country in the late eighties—and still today—were gay men). As Basile said, the National Rifle Association—which he cited several times as an example of savvy politicking, albeit one at the opposite end of the political spectrum from himself and which is frequently criticized for “buying” politicians—“don’t want you to see a redneck out there; they want you to see a family man. Nobody relates to the redneck, or, if they do, they [NRA] want to keep a distance from them.”⁴⁷⁵

The board of AIDS Action Council was pleased enough to have Jean McGuire at the helm of the organization because she was perceived as a heterosexual woman. Fortunately for people with AIDS, who would benefit from the political accomplishments of McGuire and other lobbyists and activists, the council wound up getting in McGuire a gifted political strategist who understood the necessity of working within coalitions to advance the mutual interests of participating organizations. McGuire brought to the council an impressive Washington résumé that included stints working on issues related to the elderly, substance abuse, and, what would become most crucial to her work with AIDS, people with disabilities. She was used to bringing together a number of organizations that had a particular interest in an issue, getting them to agree to speak with a unified voice, and then going to Congress as a bloc that could wield considerable political clout. She also was used to sur-

⁴⁷⁵. Vic Basile, interview with author, Washington, DC, 8 July 1996.

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rounding herself with others who could play the game of Washington politics by the same rules, and as well, as she did.

McGuire's right-hand man at AIDS Action Council was Tom Sheridan, a former social worker turned lobbyist who went to the council from the Children's Defense Fund. Like McGuire, Sheridan understood the importance of coalition politics, the give-and-take that members must agree to in the interest of a greater good. Sheridan told me, "Coalition politics is effective because it's the hardest to get people to do. The Hill really respects it because they figure that if you can get up here with a coalition that big and that diverse and have everyone agreeing on something, you must have hit on something."⁴⁷⁶ Also like McGuire, Sheridan was "horribly closeted at the time," as Basile described him. "At the first mention of 'gay' he would go ballistic."⁴⁷⁷

McGuire and Sheridan were instrumental in organizing a coalition of organizations in Washington that in some way had a vested interest in AIDS, either because of the nature of their business (medical groups, for example) or the clients they represented (such as disability organizations). The coalition, called National Organizations Responding to AIDS (NORA), included the national gay groups. But for the first time since the beginning of the epidemic, the gay groups were no longer the principal spokespeople on AIDS.

NORA depended on the "mainstreaming," or de-gaying strategy—something that couldn't be accomplished if the coalition was perceived as simply a gay ploy for attention and mon-

⁴⁷⁶. Thomas Sheridan, interview with author, Washington, DC, 24 February 1995.

⁴⁷⁷. Basile interview.

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ey. Sheridan explained, “We tried to make sure that ‘the table’ looked like the epidemic, and that no one was left out and no one was distanced. HRCF had a seat at the table. NGLTF had a seat at the table. But the nurses’ association had a seat at the table as well. Disability rights groups had a seat at the table. The ACLU had a seat at the table.”⁴⁷⁸

NORA had a membership of about sixty health, labor, religious, professional, and advocacy organizations at the time. Among those representing “mainstream” national organizations were Curt Decker, who, besides helping to organize the MACS study in Baltimore, lobbies on disability issues in Washington, and Patrisha Wright, a lesbian who lobbied for the Disability Rights and Education Fund from 1979 to 2005. There was Bill Bailey, a powerhouse lobbyist for the American Psychological Association who pushed Congress and the administration relentlessly on HIV prevention. And there were others as well whose willingness to be open about their sexual orientation within their organizations, to demonstrate the relevance of AIDS to their organizations’ interests, and to devote untold hours to AIDS policy work despite their employers’ expectations that they also work on other policy issues, served not only to bolster support for NORA but in some cases to affect entire professional disciplines. When Bailey died from AIDS in 1994, for example, the American Psychological Association established a William A. Bailey Congressional Fellowship Fund “in recognition of his advocacy on behalf of AIDS-related psychological research, training, and services.”⁴⁷⁹

⁴⁷⁸. Sheridan interview.

⁴⁷⁹. Aras van Hertum, “Bill Bailey, Influential Lobbyist on AIDS, Dies at 34,” *Washington Blade* (29 April 1994), 31.

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Besides AIDS Action Council's McGuire and Sheridan, the inner circle of NORA during the years when it scored big wins on Capitol Hill, 1988 to 1990, included a young lawyer, frequently described in Washington's gay political circles as "brilliant," named Chai Feldblum. Just finished with a clerkship for Supreme Court Justice Harry Blackmun, Feldblum followed her longtime friend Tim Westmoreland's suggestion that she explore her interest in public law at AIDS Action Council. Like McGuire, Feldblum was identifying herself as "bisexual" at the time. Hired for a salary that was equivalent to what her fellow Harvard Law School grads were being paid as bonuses for joining the nation's major law firms, Feldblum was soon in the thick of AIDS politics. In her second week at the council, Senator Jesse Helms introduced his "No Promo Homo" amendment. The AIDS lobby was caught offguard with no strategy to counter Helms's gay baiting, and with no one else at that point to take their side. Feldblum said, with considerable understatement, "For me, that was a very poor start." Within three months she left AIDS Action Council, and went to the ACLU's AIDS Project. Shortly afterwards, Jean McGuire became the council's director.

The pieces were in place—at the power center of the coalition two sexually ambiguous women and a closeted gay man—to propel NORA into the winner's circle it hadn't yet occupied since the group was first convened in 1986. McGuire became the group's strategist, Sheridan its key lobbyist, and Feldblum, by now at the ACLU, was the coalition's "legislative lawyer"—a term coined by Feldblum for the team member who, through research into a bill's legislative history (the accumulated committee reports, testimony, and records of discussion surrounding legislation being considered by the House or Senate), provides the group with the language it needs to frame an argument in a way that will win support on Capitol Hill. As Feldblum put it, "'Winning' in the congressional process means winning

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something, and then if you're a good player you win the *most* that you can get given the constraints."⁴⁸⁰

NORA mobilized its forces to take away as its spoils the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act and important protections for people with AIDS under the Americans with Disabilities Act (ADA), both in 1990. Named after the Indiana teenager who died of AIDS just four months before the bill was passed, the CARE Act provided funding to the cities and states hardest hit by the AIDS epidemic to pay for services for people with HIV. Crafted by Jean McGuire, Tom Sheridan, GMHC's Tim Sweeney, and Pat Christian, who at the time was the policy director for the San Francisco AIDS Foundation, the CARE Act's first two years alone provided more than \$847 million to fund AIDS services nationwide.

When Congress in spring 1996 finally reauthorized the CARE Act for another five years, it was being funded to the tune of \$738.5 million in fiscal 1996 alone.⁴⁸¹ In fiscal 2011, the now-\$2.3 billion CARE Act program ranks third, behind Medicare and Medicaid, among federal programs that account

⁴⁸⁰. Chai Feldblum, interview with author, Washington, DC, 12 April 1996.

⁴⁸¹. Sue Fox, "While Signing CARE Act, Clinton Calls for Educating Gay Youth," *Washington Blade* (24 May 1996), 14.

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for a total \$14.1 billion spent on taxpayer-supported domestic HIV-related care and support services.⁴⁸²

The CARE Act certainly was a juicy plum for AIDS Action Council's member organizations, and has been a tremendous source of funding for much-needed services for people with HIV/AIDS. But the ADA, also passed in 1990, offers an even clearer example of how the council was able to achieve a significant legislative win for people with AIDS by maneuvering within the NORA coalition.

The ADA expanded on earlier federal antidiscrimination laws protecting people with disabilities, in such areas as employment and public accommodations, by redefining discrimination to include not only outright discriminatory actions against a disabled person but also the absence of taking certain affirmative steps to *accommodate* people with disabilities. Under the law, for example, an employer is required to make "reasonable accommodations" for applicants and employees who are disabled but who are otherwise qualified to do a job.⁴⁸³ People with AIDS were covered under the law because the Supreme Court in

⁴⁸². Kaiser Family Foundation, HIV/AIDS Policy Fact Sheet: US Federal Funding for HIV/AIDS: The president's FY 2011 Budget Request, February 2010. At <http://www.kff.org/hivaids/upload/7029-06.pdf>, accessed 17 May 2011. NOTE: I have cited the president's requested FY2011 budget figures because at production time, the FY 2011 budget still had not been approved by Congress and signed by the president.

⁴⁸³. See Chai R. Feldblum, "Antidiscrimination Requirements of the ADA." In Lawrence O. Gostin, Henry A. Bayer, eds., *Implementing the Americans with Disabilities Act: Rights and Responsibilities of All Americans* (Baltimore, Md.: Paul H. Brookes Publishing Co., 1993), 35–54.

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1987 ruled in *School Board of Nassau County v. Gene H. Arline* that contagious diseases, including AIDS—though technically an infectious, not a contagious, disease—are considered a handicap or disability, and are therefore protected under federal disability law.⁴⁸⁴ In its first AIDS-specific decision, the Supreme Court in 1998 ruled that asymptomatic HIV infection qualifies as a protected disability.⁴⁸⁵

Curt Decker and Pat Wright were seasoned team players in the Consortium of Citizens with Disabilities. Decker and Wright showed both the consortium and the NORA coalition how AIDS was relevant to the disability lobby, and why the AIDS lobby would gain from an alliance with the established disability groups. Decker recalled that he tried to interest disability organizations in AIDS well before the passage of the ADA. “I kept

⁴⁸⁴. Diane M. Gianelli, “High Court Ruling Gives Basis for AIDS Bias Suits,” *American Medical News* (13 March 1987), 1.

⁴⁸⁵. Joan Biskupic and Amy Goldstein, “Disability Law Covers HIV, Justices Rule,” *Washington Post* (26 June 1998), 1. The case before the court, *Bragdon v. Abbott*, was brought by Sidney Abbott after a Bangor, Maine, dentist, Randon Bragdon, refused to fill a cavity for her after Abbott checked off “yes” to the question of whether she was infected with HIV on a routine questionnaire in the dentist’s office. Bragdon claimed Abbott was not protected by the ADA because she was merely HIV-positive and had no AIDS-defining conditions. Abbott claimed that indeed she was “substantially limited” in a major life activity—a criterion for a condition’s being considered a disability under the ADA—in that her reproductive choices were affected by her fear of transmitting HIV to a child and not living long enough to rear it. The court made clear that HIV-positive Americans are protected from discrimination from the moment they become infected.

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pushing the disability community to look at AIDS as a disability before there was a NORA,” he said. “I told them that if they couldn’t embrace it, they should realize that a fair amount of their constituency—such as substance abusers and the mentally retarded—might become infected.” If that didn’t persuade them, Decker added that “given the stigma associated with this disease, it was going to backlash.”⁴⁸⁶

As the ADA made its way through Congress, from its earliest drafts in 1987 to its passage in 1990, there were a number of attempts by hostile members to split apart the disability and AIDS coalitions by driving a wedge between the mentally ill and people with AIDS. Fortunately, said Decker, “The disability community realized what was going on, and said we may not be thrilled about AIDS, but we realized this was trying to slice off unpopular communities—and twenty years ago that was us, with forced sterilizations.”⁴⁸⁷

One attempt to “slice off” protections for people with HIV and AIDS from the ADA was the so-called Chapman food-handler amendment, which would have prevented HIV-positive food handlers from claiming protection against discrimination. When the amendment passed the House and Senate in the spring of 1990, the disability lobby and NORA joined forces in opposing it.

The disability and AIDS coalition argued that AIDS is a disability and must be protected under the ADA. Chai Feldblum, recognized by *The American Lawyer* as one of the nation’s leading experts on the ADA, said, “What was key was that the

⁴⁸⁶. Curtis Decker, interview with author, Washington, DC, 13 February 1995.

⁴⁸⁷. Decker interview.

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disability community as a whole was fighting the amendment. When we went to meetings at the White House there would be fifteen people around the table—ten of them with disabilities, and only two of them whose disability was AIDS. People in wheelchairs, people with cerebral palsy, people who were blind—they were all saying this is a bad amendment.”⁴⁸⁸

Despite the major political victories in the ADA and the CARE Act—the first and only disease-specific law in U.S. history⁴⁸⁹—Jean McGuire never wavered from her belief that AIDS Action Council’s ultimate objective, indeed that of all AIDS organizations, was to mainstream the AIDS issue to the point that AIDS organizations per se would no longer be needed. “Our goal,” she recalled saying at the time of the fight for the ADA, “has to be some level of integration of this obligation into the other health care structures.”⁴⁹⁰

Mainstreaming, or de-gaying, AIDS was a shrewd strategy and worked to bring about major legislation with tremendous benefits for people with AIDS. In the process, though, what happened is that politicians ate up the idea that they could “do something for AIDS” by helping women and kids—as small a segment of the AIDS population as they may have been. Gay men with AIDS certainly benefited from the ADA and Ryan White CARE Act. But it was hardly coincidental that the CARE Act was named after a white teenager from middle America who contracted HIV in a “respectable”—nonsexual—way from

⁴⁸⁸. Feldblum interview.

⁴⁸⁹. Martha M. McKinney, “Consortium Approaches to HIV Services Delivery Under the Ryan White CARE Act” (Washington, DC: US Department of Health and Human Services, 1993), iii.

⁴⁹⁰. McGuire interview.

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blood products to treat his hemophilia. Despite the widespread attention his diagnosis and death brought to AIDS, it was politically inconceivable there would be a “Rock Hudson CARE Act.” To win support on Capitol Hill, the unprecedented suffering of a seemingly selected group of Americans was downplayed by lobbyists forced to play by the rules of a political system that doesn’t value the lives of gay people.

Only in retrospect is there acknowledgment that playing by those rules may have been deleterious to the gay civil rights movement, whose main goal, after all, is to get the nation’s political leaders to value the lives of gay Americans as much as those of nongay Americans. Urvashi Vaid wrote in *Virtual Equality*, “Today, there is broad acknowledgment among gay and AIDS leaders that the de-gaying of AIDS was a conscious political choice made by gay organizers in the mid-eighties.” But she added, “With our frequent pleas to the government to spend funds for AIDS because straights can get ill too, we promoted the homophobic subtext that AIDS would not be as important if only gay or bisexual people were susceptible.”⁴⁹¹

Looking back on the effort to “de-gay” AIDS, former HRCF director Tim McFeeley put a very fine point on his critique of the strategy that HRCF actually supported. It seemed the only viable option, he said, was to “make people afraid in the straight community.” The lobbyists talked about women and children at risk, downplaying the fact that the overwhelming majority of AIDS cases in the country were among gay men and injection drug users (IDUs). Said McFeeley, “Gay people—leaders, organizers—were suffering from feeling that we need to portray ourselves as victims, and that nothing can come out of the government, so therefore we need to be slyly strategic by saying,

⁴⁹¹. Vaid, *Virtual Equality*, 75.

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‘This isn’t about gay people; this is your sons and daughters, Mr. and Mrs. America.’”

But, McFeeley added, “There’s no less hurt because it’s affecting gay men and IDUs—and that’s all we had to say.”⁴⁹²

⁴⁹². Timothy McFeeley, interview with author, Washington, D.C., 26 June 1995.

TWENTY-TWO

In the spring of 1995, AIDS advocates in Washington, now representing organizations that had become community institutions—even referred to as “mainstream”—and part of a nationwide “industry” supported by the CARE Act, fought against each other and against any cuts that Republicans in Congress might try to make when the act came up for reauthorization. Meanwhile, a contingent of forty-five gay elected officials from across the country—including mayors and state legislators—was met by Secret Service guards wearing bright blue rubber gloves as they checked the officials’ bags and briefcases before letting them into the White House, where they’d been invited for a June 13, 1995, meeting. Administration officials were appalled and apologized profusely. Vice President Al Gore made a point of shaking all the gay officials’ hands at a reception afterward to show that at least he wasn’t afraid of “catching” AIDS from them.

The week before this insulting action—which gay activists promptly dubbed “Glove-Gate”—the Clinton Justice Department had declined to file a friend-of-the-court brief challenging the constitutionality of Colorado’s antigay Amendment Two, a measure intended to prohibit gay people from being protected by antidiscrimination laws, as it came before the Supreme Court. A year later the Supreme Court overturned the Colorado law as unconstitutional—with no input from the supposedly gay-friendly Clinton administration.

Hoping once again to smooth over his bumpy relationship with the gay community, President Clinton used the occasion of the meeting with the gay officials to present his new liaison—

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the White House's first-ever—to the gay community: Marsha Scott, a nongay woman whose only qualification for the job seemed to be that she had gay friends and was, naturally, a longtime Friend of Bill's. Of course Clinton apologized for the glove incident, portraying it as nothing more than just another of the numerous lapses of judgment under his watch.⁴⁹³

Clinton offered unprecedented access to gay and lesbian leaders because they had given millions of dollars and strong political support to his 1992 campaign. He had won many gay hearts, and pulled in huge contributions from the community, when he recognized gay people's efforts and suffering in the AIDS epidemic. In a historic speech during the 1992 campaign, Clinton said to a group of gay and lesbian supporters in Los Angeles: "I just want to thank the gay and lesbian community for your courage and your commitment and your service in the face of the terror of AIDS. When no one was offering a helping hand, and when it was dark and lonely, you did not withdraw, but instead you reached out to others. And this whole nation has benefited already in ways most people cannot even imag-

⁴⁹³. I have based this reporting on several articles: Al Kamen, "Guards Don Gloves as Gay Officials Visit White House," *Washington Post* (15 June 1995), 1; Lou Chibarro, Jr., "Secret Service Dons Rubber Gloves to Search Officials," *Washington Blade* (16 June 1995), 1; Frank Rich, "The Gloved Ones," *New York Times* (18 June 1995); Lou Chibarro, Jr., "Clinton Apologizes for Glove Incident," *Washington Blade* (23 June 1995), 1; Linda Greenhouse, "Gay Rights Laws Can't Be Banned, High Court Rules," *New York Times* (21 May 1996), 1; Frank Rich, "A Gay-Rights Victory Muffled," *New York Times* (22 May 1996), A17; and David W. Dunlap, "Clinton Names First Liaison to Gay and Lesbian Groups," *New York Times* (14 June 1995).

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ine from the courage and commitment and sense of community which you practice.”⁴⁹⁴

Once in office and put to the test of hostile opinion from conservatives in Congress, however, Clinton did not keep his word to the gay community. As Urvashi Vaid pointed out in *Virtual Equality*, “All the access in the world has not strengthened our ability to pass pro-gay legislation or to hold the president to his campaign promises.”⁴⁹⁵ “Glove-Gate” brought home once again the fact that even an invitation to the White House didn’t mean gay people had been invited finally to participate as equal citizens in the land of *e pluribus unum*. The influx and visibility of so many gay men and lesbians in the gay political movement in the late eighties because of AIDS had not led to genuine political clout at the national level.

The political strategy to “de-gay,” or mainstream, AIDS had worked to gain support from frightened heterosexuals—but then it backfired by having the unintended effect of separating AIDS advocacy from the gay rights movement. The gay organizations effectively turned over the leadership role on AIDS to degayed, so-called mainstream organizations, such as AIDS Action Council.

The treatment of gay officials at the White House made clear that, no matter how vigorously gay lobbyists denied and downplayed the connection of gay people and AIDS, the American public and its leaders still viewed all gay people as potential vectors of HIV, regardless of their antibody status and no matter how casual the contact with them. Ben Schatz, who

⁴⁹⁴. Quoted in David Mixner, *Stranger Among Friends* (New York: Bantam, 1996), 239.

⁴⁹⁵. Vaid, *Virtual Equality*, 129.

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wrote AIDS policy papers for Clinton's 1992 campaign, said that even the accessible, often gay-supportive president saw "no differentiation" between the politics of AIDS and the movement of gay people for equal rights.⁴⁹⁶

As happened with young gay men who believed that "gay" and "AIDS" were synonymous, even the president didn't distinguish the two. Why, then, did the gay groups believe their own de-gaying rhetoric about women and children first and gay men last? Where and how did AIDS advocacy split apart from the gay rights movement? And what were the implications of turning over the political reins on AIDS to advocates and organizations that sometimes went out of their way to distance themselves from the gay community? Clearly the advocates hadn't succeeded in de-gaying AIDS in the minds of the public. But what did it mean that they had degayed it in their *own* minds?

Some argued that gay people needed to look beyond AIDS, to resume the work of gay liberation that had begun in the seventies and was interrupted to a great extent by the community's desperate need to mount a response to the epidemic. In a seminal article in the *Nation*, Darrell Yates Rist, a gay writer who later died from AIDS, challenged gay people to look beyond the AIDS epidemic in thinking about a community with many long-term needs and challenges that were largely set aside because of the immediate demands of all the sickness and death in the community. The gay civil rights movement shouldn't be subsumed by the AIDS epidemic, said Rist, because not all gay men, and certainly not many lesbians, would die of AIDS. He said that the divorce of AIDS from the gay movement was a "route to respect for homosexuals not open to unapologetic gay activists." But the support that gay people received from non-

⁴⁹⁶. Benjamin Schatz, interview with author, San Francisco, 2 February 1995.

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gays too often came at the price of their gay identity. As Rist put it, “Even homophobes who’d never want to see a homosexual holding a lover’s hand, especially in front of the children, can cry (and contribute) at the thought of so many gay men dying.”⁴⁹⁷

In an *Out/Look* article that sounded similar themes to Rist’s, Eric Rofes asked, “De-gayng AIDS might bring more funding, but isn’t the cost too high?” Rofes cited a number of examples of AIDS organizations that were created by gay people, still largely staffed by, and providing services to, gay men with HIV and AIDS, but that downplayed their connection to the gay community. He noted, for example, that although the majority of participants in an AIDS Project Los Angeles walkathon were gay men and lesbians, there was no acknowledgment during the opening ceremony of this community, while speakers mentioned other affected populations. Flyers for Boston’s AIDS Action Committee’s “Pride Dance,” during a lesbian and gay pride weekend, hadn’t even mentioned the gay and lesbian community.

Perhaps most remarkable of all, Gay Men’s Health Crisis advertised itself only by its initials, with the letter “H” underlined to emphasize “health” and to deemphasize the word “gay.”⁴⁹⁸ GMHC staff members have told me the agency retained the word “gay” in its name simply to honor its six gay founders.

Urvashi Vaid said that the receipt of government money has compromised AIDS service organizations. “They don’t want to

⁴⁹⁷. Darrell Yates Rist, “AIDS as Apocalypse: The Deadly Cost of an Obsession,” *The Nation* (13 February 1989), 181.

⁴⁹⁸. Eric Rofes, “Gay Groups vs. AIDS Groups: Averting Civil War in the 90s,” *Out/Look* (Spring 1990).

VICTORY DEFERRED

rock the boat,” she said. “They have to work with Republicans and Democrats to get their money. So they end up not taking forceful political positions.”⁴⁹⁹ This is why, she said, the HIV-related interests of gay people can be represented only by independent gay organizations, not “mainstream” AIDS groups on the public dole from the Ryan White CARE Act. But the gay rights organizations were only too happy to leave AIDS to the AIDS groups, even if they marginalized gay men in the same way as the mainstream organizations they were meant to supersede.

In his *Out/Look* article, Rofes articulated what really was behind the de-gaying strategy of gay AIDS advocates, and what led the gay rights organizations to surrender their stake in the politics of the epidemic to the degayed AIDS industry: embarrassment about gay male sex. Diverting the spotlight that had been shined by the news media and others from what gay men do in bed, as well as what some do in less private places, helped AIDS advocates to win support and funding from the government. So gay advocates downplayed gay men’s sexuality, pointing out that gay men really had become “good” homosexuals, evidenced by declining rates of new HIV infections. By de-gaying AIDS, advocates won government funding for AIDS services—but gay men were made eunuchs in the process.

Some, mainly people with AIDS, argued that the gay community had abandoned AIDS because it was too distracting from other political priorities. In a probing cover story in the *New York Times Magazine* in late 1993, reporter Jeffrey Schmalz, who died from AIDS just before the article’s publication, asked, “Whatever happened to AIDS?” The gay movement, he wrote, “has pushed AIDS to the sidelines.” As proof Schmalz contrasted the overriding “themes” of the 1987 and

⁴⁹⁹. Vaid interview.

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1993 gay and lesbian marches on Washington. In 1987, AIDS carried the day as people with AIDS led the march and the AIDS Memorial Quilt was displayed for the first time. The 1993 march, on the other hand, was dominated by the issue of gays in the military—which previously had been a low-level priority on the gay movement’s agenda until it was catapulted to the forefront by President Clinton’s 1992 campaign promise to end discrimination against gay people in the armed forces.

Schmalz quoted former NGLTF director Torrie Osborn, who argued that the shift in gay political priorities was inevitable with the election of a Democratic president, renewed attacks from the right wing, and just plain burnout. Schmalz noted that many gay people, particularly those who did not have HIV, didn’t want the gay community to be defined by a disease. Osborn said, “There is a deep yearning to broaden the agenda beyond AIDS. It’s one thing to be fighting for treatment, believing you’re going to get a cure that will have everyone survive. But it’s an incredibly depressing truth that AIDS has become part of the backdrop of gay life.”⁵⁰⁰

Not all gay people, including men who didn’t have HIV, believed that AIDS should simply be relegated to being “part of the backdrop of gay life.” As they continued to see their friends get infected with HIV and struggle to pay for treatments to keep them alive, they still viewed AIDS as a profoundly “gay” issue. But they questioned whether the gay community’s political organizations were willing and able to keep AIDS on the front burner as they simultaneously worked to address other community priorities. They also questioned whether a compromised and degayed AIDS industry could effectively serve the gay men

⁵⁰⁰. Jeffrey Schmalz, “Whatever Happened to AIDS?” *New York Times Magazine* (28 November 1993).

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who to this day comprise the majority of new infections and AIDS cases in most areas of the country.

The street activist in him showed when Paul Boneberg said, “I would argue that we should go back to what was before AIDS activism—that is, community activism, constituencies who are at risk—and serve those constituencies relative to AIDS.” AIDS organizations are doing what they need to do as organizations, by raising money and trying to garner political and community support for their work. But they are unable to be forceful voices for gay people with AIDS because they are compromised by taking public funds—however necessary those funds are to their operation. Boneberg told me, “The lesbian and gay community’s leadership has to reassert responsibility, and that will mean disagreeing with AIDS groups, many of which are led by gay people. But so be it.”⁵⁰¹

Many among the community’s leadership had come into the gay civil rights movement because of AIDS. In fact, said historian John D’Emilio, “AIDS built the gay movement. It shook loose the resources to transform a movement that was small and based almost entirely on volunteer labor into a movement of full-time people who were devoting themselves to this work and getting paid for it.” He added, “Slowly in time that transition would have happened, but the epidemic compressed all of the change that might have taken a generation basically into a decade.”⁵⁰²

The growth of both the AIDS groups and the professional gay political organizations “created a shift in the leadership of

⁵⁰¹. Boneberg interview.

⁵⁰². John D’Emilio, interview with author, Washington, DC, 24 May 1996.

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the gay movement, accentuating the trend toward leaders who can claim professional expertise instead of activist credentials,” as Dennis Altman put it.⁵⁰³ But, as he also pointed out, these “new bureaucrats” faced alienation from the gay and lesbian rank-and-file who became involved in AIDS work because the epidemic was affecting people they knew, or even possibly themselves. Credentials as a gay activist or even, at times, experience working in the “field” of AIDS were no longer necessary prerequisites for leadership positions in the AIDS organizations created by and for gay people.

A 1996 advertisement for AIDS Action Council executive director captured this quite clearly. Although the ad was placed in the *Washington Blade*—presumably the job would be open to a lesbian or gay man reading the gay community newspaper—the only mention of the word “AIDS” itself was in the title of the organization. Neither AIDS activist experience nor gay political leadership experience was required. Besides the experience necessary for managing a not-for-profit organization of a similar size, required skills for the job included financial and budget management, fund-raising, and excellent communications abilities. “The executive director,” said the ad, “should be a team builder, coach and a highly skilled consensus manager.”⁵⁰⁴

The de-gaying of AIDS was now complete in the minds of AIDS advocates as the nation’s leading AIDS advocacy group, created in 1984 to represent the AIDS organizations that had

⁵⁰³. Dennis Altman, “Legitimation through Disaster: AIDS and the Gay Movement.” In Elizabeth Fee, Daniel M. Fox, eds., *AIDS: The Burdens of History* (Berkeley: University of California Press, 1988), 309.

⁵⁰⁴. “AIDS Action Executive Director,” quarter-page advertisement in *Washington Blade* (31 May 1996), 32.

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been founded and run by gay people, looked for an executive director who was simply a well-spoken fundraiser and “coach.” Now gay rights organizations felt they could return to the business of gay and lesbian liberation—despite an ongoing epidemic that continued to kill tens of thousands of gay men—because AIDS was being “taken care of” by the AIDS industry.

Few stopped to think that any industry, even one created by gay people, is above all interested in its bottom line and self-perpetuation. In the case of AIDS organizations, that meant preserving their funding at all costs, even when they felt it required them to dissociate themselves from the community that gave them life in the first place.

Of course this set up a curious paradox for these organizations: How could they continue to be *in* the gay community but not *of* it? More to the point, how would they keep gay people giving money and serving as volunteers in unprecedented numbers in organizations they helped to create but that now at times wouldn't even acknowledge them?

TWENTY-THREE

While the gay movers and shakers were doing their thing in Washington, of course, ACT UP and other activists “outside the Beltway” also were doing theirs. Sometimes there was synergy between the direct-action activists and the professional pols in Washington. At other times there was disagreement, even rancor, over strategy. And every once in a while, a split personality would emerge in Washington who had a sense of when politics should give way to protest, who could appreciate the exigencies of federal politicking while still believing there are limits to politeness and times when what is expedient and achievable must come second to what is necessary and right.

Urvashi Vaid had thrived on the excitement and challenge of direct-action activism since her early gay community-organizing days in Boston. Her assistance with publicizing ACT UP’s 1988 FDA demonstration to the press was only natural given her love of street politics and the extensive media contacts she had cultivated throughout her years as NGLTF’s media director. But in Washington, Vaid sometimes ran up against the hardheaded pragmatism of polished gay politicians who didn’t have much use for direct action. As she put it in *Virtual Equality*, “Although some veterans of the post-Stonewall generation embraced ACT UP as a return to the radical politics they felt the gay movement had wrongly abandoned, most gay political veterans looked down on direct action in general.”⁵⁰⁵

⁵⁰⁵. Vaid, *Virtual Equality*, 101.

VICTORY DEFERRED

Vaid recalled that at the meeting between gay and AIDS lobbyists and FDA bureaucrats immediately after the FDA demonstration, the lobbyists put forth the same message as ACT UP, yet they consciously positioned themselves as the “more reasonable” alternative. For their part, Vaid said, ACT UP members “were contemptuous of and hostile to the mainstream gay and lesbian rights movement.” Small wonder, then, that often there was such ill will between the coat-and-tie lobbyists and the in-your-face protestors.

Jeff Levi, who was NGLTF’s executive director at the time of the FDA demonstration, was critical of the limited awareness of gay history prevalent among many in ACT UP, those, he said, who “think there was no organizing, no politics before ACT UP.” Nevertheless, Levi credited ACT UP’s media-grabbing protests with providing a useful backdrop against which gay political operatives could move and shake the Washington power establishment. “While we recognized that we did the coat-and-tie routine more often than not,” he said, “the street activists played a critical role in helping us get that access. They moved the range of reasonableness more to the left than it might otherwise have been.”⁵⁰⁶

To Larry Kramer and many other advocates of direct action, the gay Washington lobbyists were little more than sycophants of the system. In a strongly worded letter to HRCF, Kramer wrote, “I resent your organization. I resent just about every gay and AIDS organization in Washington. For you see, I don’t know what you *do*. I don’t know what any of you *do*, down there.” To underscore his lack of understanding of what the gay lobbyists were doing in Washington, Kramer distilled his complaints to a typically enraged, self-interested, and highly per-

⁵⁰⁶. Levi interview.

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sonal closing jab: “What are you doing to save my fucking life?”⁵⁰⁷

Kramer was not the only one in ACT UP who didn’t understand what the gay lobbyists do in Washington. Chai Feldblum described the tensions between pragmatic lobbyists, who played to win as much as they could in Congress, and those who were not familiar with this Washington style of politics. She said, “That caused conflict between the ‘inside the Beltway’ folks and the ‘outside the Beltway’ folks who said, ‘Why are you putting forward this amendment that seems to be giving something up? We want to fight to the max.’ Well, if you fight to the max and, as we say, go down in flaming glory on the Senate floor, you’ve got a lot of flaming glory and a lot of ashes. But you don’t have any program that helps people with AIDS.”⁵⁰⁸

Most of the gay and lesbian Washington lobbyists I interviewed in the nineties, like Levi, were quick to say that ACT UP helped them do their work. The activists pushed the limits of lawmakers’ patience to the point that the legislative language offered by the lobbyists—often a legalese version of the activists’ own demands—looked reasonable. Some lobbyists went so far as to credit ACT UP’s trailblazing for much of their success in getting the government finally to help people with AIDS. On the receiving end of both the lobbying and demonstrations, President Clinton’s first two AIDS “czars” also credited ACT UP with moving the government to make necessary changes.

Kristine Gebbie said, “I think the anger displayed through ACT UP protests was very useful. The intriguing thing it did was

⁵⁰⁷. Kramer, “What Are You Doing to Save My Fucking Life?” In *Reports from the holocaust*, 309–13.

⁵⁰⁸. Feldblum interview.

VICTORY DEFERRED

make 'the suits' look suddenly very wonderful and reasonable and paved the way for some conversations that might have been more difficult."⁵⁰⁹ Gebbie's successor, Patsy Fleming, said, "There were times when there was an adversarial relationship between them and us. But I think in general and on balance, it was a very close relationship and it developed and flourished over the years."⁵¹⁰

Not all the coat-and-tie lobbyists, however, were willing to give unqualified praise to ACT UP. Most of them felt that ACT UP didn't understand or value the lobbyists' role the way the lobbyists valued ACT UP's. Tim McFeeley said, "By 1989, ACT UP had done the necessary shock troop work, which is shocking people, making people understand this was being ignored and was very serious. Then as solutions started to get crafted, it turned a lot of people off and it made it very difficult to work with politicians. There was never any particular collaboration; we just sort of tolerated one another." He added, "Do I think we would have gone further without [ACT UP]? Probably not. I just wish that some of that energy had gone into more permanent activism, the activism of political organizing, as opposed to a one-hour catharsis."⁵¹¹

Urvashi Vaid learned that direct action was okay to do while she was an NGLTF staffer but that it took on added significance when she became executive director. A few months after she organized a December 1, 1989, civil disobedience in front of

⁵⁰⁹. Kristine Gebbie, interview with author, Washington, DC, 15 March 1995.

⁵¹⁰. Patricia Fleming, interview with author, Washington, DC, 22 March 1995.

⁵¹¹. McFeeley interview.

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the White House by the executive directors of a number of gay and AIDS organizations—sixty-five of them were arrested—Vaid, by then NGLTF's director, was invited to a meeting sponsored by the National Leadership Coalition on AIDS. The organization's membership, corporate CEO types, were to be treated to President George H.W. Bush's first and only speech on AIDS—which included mention of his support for the ADA, then pending in Congress, despite the opposition of many Republicans who wanted to protect businesses from the costs of making their workplaces accessible to people with disabilities.

Vaid helped organize a demonstration outside the Crystal Gateway Marriott Hotel, in Arlington, Virginia, where President Bush was to speak on that Thursday, March 29, 1990. She also tried to get other gay and AIDS organization leaders to join her in demonstrating inside. She said, "I thought it was just a matter of phoning people who had gotten arrested—they'd already protested Bush, what the hell did they have to lose?!"

In the end, no one else would join her—not Tim McFeeley, not Jean McGuire, not even San Francisco rabble-rouser Cleve Jones, who was going to meet with Bush at the White House the next day. They offered their encouragement but, one by one, all of them begged off actually joining her with demurrals like "I'll have to get my board's approval," and "There are going to be funders in the room."

Vaid followed along in a printed copy of Bush's speech she'd gotten from her media friends. "It was a very straightforward speech about non-discrimination," she recalled. "He didn't mention gay men; it was all babies and women." Toward the end of the speech, Vaid, in her "little black dress and 'Barbara Bush' pearls," stood up and said, "Mr. President, you're not doing enough. We don't need your leadership once a year; we need it every day." The crowd was stunned. They applauded

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Bush when he responded to his diminutive heckler and told the audience, “I understand the concern that these people feel. If we do nothing else, I hope we can make them understand that not only you care, but we care, too.”

“These people” indeed. At that, Vaid stood again and shouted as she held up the sign she had made the night before and smuggled into the room. On one side it said, “Talk is Cheap, AIDS Funding is Not,” and on the other, “Don’t Forget Gay People with AIDS.”

The Secret Service escorted Vaid and another heckler, from ACT UP, out of the building, threatening to arrest them if they returned. After Bush finished, Jean McGuire and Tim McFeeley held a press conference. Vaid recalled, “They took this empty chair and put it in the middle of the press conference and said, ‘Urvashi Vaid would have sat here if she hadn’t been kicked out of the speech. And we agree with what she said!’” McGuire noted at the press conference that Bush’s speech was the first time he’d formally expressed compassion for people with AIDS. She added, however, “It was long on compassion but short on commitment.”⁵¹² Vaid said she was glad that her protest at least seemed to inspire the news media to scrutinize Bush’s remarks more closely than they likely would have done otherwise.

But then she had to answer to some of NGLTF’s board members who “flipped” at what she had done without their approval. For them, her visibility as director of the organization gave legitimacy to activism that they were ambivalent about, now that they were at least getting a taste of political access. They thought it unseemly for the director of the National Gay and Lesbian Task Force to stand to protest a speech by the

⁵¹². “Bush: The Law Must Protect Rights of PWAs,” *Au Courant* (16 April 1990), 10.

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president which, in her judgment, included statements that, if translated into policy, would be harmful to gay people with AIDS.

Years later, Vic Basile still steamed over Vaid's 1990 protest. He spoke of Vaid as "a purist, an ideologue" who "basically doesn't get politics." He elaborated, "She thought it was a good idea to challenge Bush in front of this corporate community. I thought it was a disaster because we had a captive audience of corporate executives who were inclined to be supportive on AIDS. And they became a captive audience to a very embarrassing demonstration. I can't tell you how serious that was."⁵¹³

Afterward, as she rode the Metro to NGLTF's U Street offices in northwest DC, Vaid felt vulnerable. She had put herself and the reputation of her organization on the line by standing up for what she believed—to none other than the president of the United States. Her fellow gay and lesbian leaders had not stood with her. Being the savvy pols they were, of course, they were able to capitalize even on this rather embarrassing breach of protocol.

But Vaid didn't have too much time to reflect on all of this once she got back to the office. "The minute I walked into the office the phone was ringing," she recalled. "It was Larry Kramer."⁵¹⁴ Naturally he was calling to congratulate Vaid for her courage and brazenness, much like his own when he heckled Bush's predecessor in the White House when he finally spoke publicly about AIDS after six years of abject silence about the epidemic. Vaid had embarrassed gay lobbyists who were willing

⁵¹³. Basile interview.

⁵¹⁴. Vaid interview.

VICTORY DEFERRED

to do whatever they had to do—even downplaying the suffering of their own people—to be allowed a place at the table. Many other gay people, however, were proud to know that not all their leaders in Washington were willing to grovel under the table for political crumbs.

Of course Larry Kramer had never groveled under anyone's table, and he wasn't about to start now. In March 1990, the same month as Vaid's one-woman protest, Kramer shocked even some of his own "shock troops" in ACT UP. In his monthly "Kramer vs...." column in ACT UP/New York's *OutWeek* magazine, he called upon "every human being who wants to end the AIDS epidemic" to be in San Francisco from June 20 to 24, at the Sixth International Conference on AIDS, "screaming, yelling, furiously angry, protesting, at this stupid conference." Lest anyone miss his point because of its subtlety, Kramer continued, "WE MUST RIOT! I AM CALLING FOR A FUCKING RIOT!"⁵¹⁵ Kramer elaborated in an interview with the *Wall Street Journal* in May. "It hurts me to say I think the time for violence has now arrived," he said. "I don't personally think I'm the guy with the guts to do it, but I'd like to see an AIDS terrorist army, like the Irgun which led to the state of Israel."⁵¹⁶

Barely three months earlier, ACT UP/New York had staged its "Stop the Church" protest against what the group considered the Catholic Church's "assault on lesbians and gays," "bias," "ignorant denial," "endangering women's lives," "no safe sex education," "no condoms," and "no clean needles." On December 10, 1989, ACT UP members invaded St. Patrick's Cathedral

⁵¹⁵. Kramer, *Reports from the holocaust* (1994 edition), 314.

⁵¹⁶. Marilyn Chase, "Demonstrations and Boycott Over Travel Curbs Threaten to Disrupt International AIDS Meeting," *Wall Street Journal* (8 May 1990), A26.

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to incarnate their anger within the church itself. Douglas Crimp and Adam Rolston participated in the protest. This is how they described it: "During high mass inside the church, angry protestors forced [Cardinal] O'Connor to abandon his sermon. Affinity groups lay down in the aisles, threw condoms in the air, chained themselves to pews, or shouted invectives at the cardinal. One former altar boy deliberately dropped a consecrated Communion wafer on the floor. (The media had a field day with that one: by the day after the event, it had become legions of 'homosexual activists' desecrating the host.) Forty-three activists were arrested and dragged out of the cathedral; another sixty-eight were arrested in the streets."⁵¹⁷

ACT UP members seemed surprised that so many people, including many gay activists, were shocked and disgusted by their use of intimidation tactics so like those of Operation Rescue, the anti-abortion group they deplored. But even gay activists were beginning to tire of ACT UP's shenanigans, concurring with Randy Shilts in his *San Francisco Chronicle* column after the demonstration at St. Pat's and several protests by AIDS activists in other cities, "If I didn't know better, I'd swear that the AIDS protestors who have been disrupting services and vandalizing Catholic churches...were being paid by some diabolical reactionary group dedicated to discrediting the gay community."⁵¹⁸

And now Larry Kramer, the nation's most prominent AIDS activist, was calling for a riot in San Francisco during the world's premier scientific conference on AIDS. As it happened,

⁵¹⁷. Crimp and Rolston, *AIDS DemoGraphics*, 138.

⁵¹⁸. Cited in Robert M. Wachter, *The Fragile Coalition: Scientists, Activists, and AIDS* (New York: St. Martin's Press, 1991), 63.

VICTORY DEFERRED

the conference would be going on at the same time as the Lesbian and Gay Freedom Day Parade, which typically drew upwards of three hundred thousand people to San Francisco. Conference organizers feared there would be massive disruptions by people who took Kramer at his word.

Ron Stall, a medical anthropologist then at the University of California–San Francisco’s Center for AIDS Prevention Studies, said in a letter to the conference’s local organizing committee, “The size of this year’s parade will swell as a result of the understandable wish to use the conference as a stage for a show of force by a community under attack. This has created what seems to me to be a scary situation: There will be a lot of affected (and infected) people locked out of a conference that is about their survival and the survival of the people they love. The closest analogy in American political history that I can think of is to the situation of Chicago in 1968.”⁵¹⁹

San Francisco activists also were on edge about Kramer’s incendiary words, which they feared this time might spark actual fires and other destruction. Paul Boneberg, then director of Mobilization Against AIDS, believed strongly that leaders must take responsibility for protecting anyone who joins a political protest that they organize. He was shocked that Kramer would launch a firebomb to land on San Francisco without necessarily planning to be there himself. Boneberg sent a letter to Kramer on June 20, saying, “For God’s sake, Larry, accept the responsibility of your position as the most famous AIDS activist in America and retract your call for violence around AIDS. You are putting our community in an even more dangerous position

⁵¹⁹. Ibid., 103.

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than it is already.”⁵²⁰ Looking back, Boneberg said, “For Larry to call on what in fact was my constituency, lesbian and gay people in San Francisco, to put themselves in harm’s way without a willingness to put himself there as well was wrong. Nobody said so because he was Larry Kramer, but I said so.”⁵²¹

As it turned out, there was no riot in San Francisco. Kramer had gone too far even for ACT UP’s street activists. ACT UP (AIDS Coalition to Unleash Power) spokesman Alan Beck said, “Our policy is nonviolent, peaceful demonstrations. We may stage sit-ins to stop proceedings, but we’ll have nothing to do with [rioting].”⁵²² While there was no full-scale riot, there were many arrests as ACT UP staged day after day of protests to grab the attention of the news media that had gathered like vultures waiting for post-riot carnage. About three hundred fifty members of the ACT UP women’s contingent were arrested after staging a “die-in” that blocked traffic on Market Street for two hours. About one thousand protestors took over the downtown branch of Nordstrom’s, claiming the department store discriminated against people with AIDS. For all its denial of being a “gay” group, ACT UP’s roots were clearly showing as demonstrators beat drums, blew whistles, and chanted, “We’re here! We’re queer! And we’re *not* going shopping!”⁵²³

ACT UP’s biggest media grab during the conference was its disruption of a speech by Louis Sullivan, secretary of Health and Human Services. Typically the head of state in whichever

⁵²⁰. Elinor Burkett, *The Gravest Show On Earth: America in the Age of AIDS* (New York: Houghton Mifflin, 1995), 20.

⁵²¹. Boneberg interview.

⁵²². Wachter, *The Fragile Coalition*, 169.

⁵²³. *Ibid.*, 216–17.

VICTORY DEFERRED

country is hosting the international AIDS conference addresses the meeting. But President George H. W. Bush declined to speak at the conference, choosing instead to attend a campaign fundraiser in North Carolina for Jesse Helms and sending Sullivan in his place. A number of AIDS organizations, including GMHC, were boycotting the conference because of the continued US policy of denying visas to people with HIV. Activists were enraged at Bush's insulting slight as well as the ongoing senselessness of excluding people with HIV from obtaining visas to enter the country.

As soon as Sullivan's name was announced, recalled Robert Wachter, the conference's program director, "the Moscone Center was transformed into Times Square at midnight on New Year's Eve,"⁵²⁴ as screaming, yelling, foot stomping, whistle blowing, and anything else that could be done was done to drown out the secretary's speech. Sullivan defiantly and bravely continued to the end of his speech—but AIDS dropped to the bottom of his list of priorities from that point on.

While the temblor of activist anger jolted San Francisco, Kramer himself remained at a safe distance—a continent away; he hadn't even gone to San Francisco after all the Sturm und Drang he'd stirred up. Of course there were rumors that Kramer would be arrested and detained for the entire time of the AIDS conference if he showed up. The question now was whether Kramer had called for a riot merely to be provocative. Was he once again speaking hyperbolically? Five years after these events, Kramer reflected, "No, I didn't mean that they should burn up everything, but I certainly think they should have been disruptive, and they were. Louis Sullivan was completely booed when he made his speech." He maintained that there should be "some kind of guerrilla warfare," though he added that he "un-

⁵²⁴. Ibid., 227.

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fortunately” wasn’t the one to do it. Harkening to his speech that led to ACT UP’s formation in 1987, Kramer said, “Considering how many people have died from AIDS, we’ve been a remarkably docile lot.”⁵²⁵

The distance ACT UP had put between itself and its founder reflected growing tensions within ACT UP itself as members disagreed about the group’s priorities and whether or not direct action itself hadn’t run its course and was no longer as effective as it had been. Only a couple of weeks after the events and nonevents in San Francisco, lesbian writer Donna Minkowitz said in the *Village Voice* that ACT UP was at a “crossroads.” In a profile of the group, she revealed that ACT UP was in fact struggling to restrain its internal divisions.⁵²⁶

The internal split in ACT UP was essentially over whether the group should continue to focus exclusively on pushing for AIDS treatments and a cure, particularly by working cooperatively inside the system with government scientists, or pursue a broader agenda of social change on issues such as racism, sexism, and homophobia. On September 13, 1990, ACT UP/San Francisco split into two chapters because of the tension between these two positions. Now there was ACT UP/Golden Gate, devoted to treatment, and ACT UP/San Francisco, which remained committed to broader social change beyond merely focusing on pushing medical science to find a cure for AIDS. ACT UP/New York, the Mother Church, also was splitting apart over similar issues, and in 1992 prominent members of the group’s central Treatment and Data Committee split off to form the Treatment Action Group (TAG).

⁵²⁵. Kramer interview.

⁵²⁶. Donna Minkowitz, “ACT UP at a Crossroads,” *Village Voice* (5 July 1990), 19–22.

VICTORY DEFERRED

Something besides merely disagreeing over the group's focus also pushed ACT UP (AIDS Coalition to Unleash Power) towards its seemingly inevitable demise. In an editorial in the *Advocate* a year after the San Francisco conference, Peter Staley, a member of ACT UP/New York who became a founder of TAG, speculated as to whether ACT UP had begun to falter. He felt that the group's power was beginning to corrupt it.⁵²⁷ But what Staley didn't seem to realize, or at least admit, was that ACT UP's *perception* of its power was what had really led it astray. Certainly the group's high media profile—assisted considerably by the traditionally made policy arguments of the Washington lobbyists—had moved federal policy-makers and scientists to change their minds about some things and, in some cases, make extremely important changes in the government's way of doing business, particularly in the area of drug development and approval.

The view from Capitol Hill of ACT UP's "power" wasn't quite as clear as Staley and others in the protest group imagined it. From his vantage point in the House, Tim Westmoreland said, "ACT UP's role was to keep media attention on the issue. I think they actually had very little effect, pro or con, on the politics of it." He added, "ACT UP was a sort of flashbulb going off on a topic. I joked several times that ACT UP's major contribution was really good graphics—and that really matters. In the eighties and nineties, it's *all* about marketing your political issue before Congress."

Good graphics and a news-grabbing flashbulb notwithstanding, Westmoreland added, "I don't think it particularly helped or hurt Congress." Like the activists at the first PWA

⁵²⁷. Peter Staley, "Has the Direct-Action Group ACT UP Gone Astray?" *The Advocate* (30 July 1991), 98.

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Lobbying Day in 1985, ACT UP typically hounded friendly law-makers. “Most of ACT UP is situated in congressional districts that are already prone to be supportive on AIDS issues to begin with,” said Westmoreland. “People didn’t go around taking over rural Georgia offices, or picketing [former California Republican Representative] Bill Dannemeyer’s office in Orange County. It was usually to get the attention of people who were already sympathetic. That doesn’t make a big difference in Washington politics.”⁵²⁸

The 1992 election of Bill Clinton, with his promise of a place at the table for gay people and a “Manhattan Project” on AIDS, robbed ACT UP of a target as big and blatant as Ronald Reagan and George H. W. Bush had been. Openly gay men and lesbians were appointed in considerable and visible numbers to positions in the Clinton administration. AIDS activists by now were fully integrated into the federal AIDS research establishment. Ginny Apuzzo became the highest-ranking open lesbian in the Clinton White House in the president’s second term. Many others took jobs in AIDS service organizations, now collecting salaries to work on behalf of AIDS and sometimes even being required to dress in business attire—both of which had been anathema to ACT UP’s radical counterculture sensibility.

ACT UP chapters throughout the country dried up for lack of interest. In early 1995, ACT UP/Kansas City was offered free, “to a good home.” In Atlanta, Jeff Graham said ACT UP had faded from visibility because so many of its members had died. He explained, “There was a sense in the late eighties and early nineties that by force of sheer willpower we could keep people alive, and we could change the world. It’s hard to continue to say with great force that, yes, we can cure AIDS, yes, we can

⁵²⁸. Westmoreland interview.

VICTORY DEFERRED

stop people dying, when people continue to die.”⁵²⁹ And in Houston, ACT UP member Eugene Harrington echoed Tim McFeeley’s critique, saying that if ACT UP had spent its energy drafting and pushing legislation rather than merely demonstrating, “we would have far more to show for that period of ACT UP activism.”⁵³⁰

As ACT UP’s demonstrations in the early nineties became more like guerrilla assaults and less like the angry but campy street theater they were famous for, the group seemed to be spinning out of control. Some believed the seeds of the group’s destruction were sown at the 1989 demonstration at St. Patrick’s Cathedral. Urvashi Vaid said, “The decline of ACT UP and direct action began, in my view, the instant concern about media coverage of actions displaced the political calculus of right or wrong.” ACT UP/New York member and GMHC staffer David Barr said of the St. Patrick’s demonstration, “The goal became more about personal expression and less about change.”⁵³¹

But the devolution of ACT UP into a group of individuals acting out their personal agendas shouldn’t have been surprising, since the group was formed intentionally as a “pure democracy,” with no apparent leaders. Its leaderlessness resulted in unchecked internal warfare as individuals formed committees and “affinity groups” to push their particular agendas. In such an atmosphere it was inevitable that one-upmanship would become the order of the day. Add to that the angry

⁵²⁹. Graham interview.

⁵³⁰. Eugene Harrington, telephone interview with author, 20 October 1995.

⁵³¹. Vaid, *Virtual Equality*, 364, 385.

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conviction that one is fighting for a “moral” cause, and it becomes apparent—to oneself, at least—that those who disagree are not only wrong, but immoral, even reprehensible, as well.

This was the attitude that many in ACT UP took toward gay leaders in Washington, the coat-and-tie set who may have been willing to shout in the streets and even be arrested in an act of civil disobedience when they felt it absolutely necessary, but who otherwise were far more comfortable debating the finer points of legislation across a conference table. By 1992, ACT UP was taking direct action against the gay and AIDS lobby in Washington. ACT UP/Seattle member Steve Michael had moved to Washington, D.C., where he regularly harassed—even physically assaulted—gay leaders. In an action that continued to reverberate negatively among gay leaders in Washington, ACT UP members in February 1992 actually handcuffed themselves to gay and AIDS lobbyists during a small meeting in Washington with CDC officials.

ACT UP asked Urvashi Vaid, who is a lawyer, to serve as their legal observer for the protest, which she agreed to do. Vaid recalled that the handcuffed lobbyists—including her immediate predecessor at NGLTF, Jeff Levi—said to her, “This is unacceptable. We won’t even talk to you until you unloose us. This is preposterous.” Vaid agreed with them. She announced, “This is not right. I’m not going to participate in this anymore. I think it’s wrong that people are being held against their will. It violates everything I believe in, and this is nuts.” So she walked out of the room. But her participation in this demonstration, despite her withdrawal when she felt the protest had crossed a moral line she wasn’t willing to cross, left an uncomfortable mark on her relationships with some gay and lesbian leaders, including Levi.

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For Vaid, the protest was “a perfect symbol of how at cross-purposes we became.” ACT UP, she said, saw the “gay establishment” as giving up too much in its desire for mainstream access and respectability. She agreed that this sometimes was the case. “But the self-righteousness and smugness by some gay activists against the gay establishment was wrong,” she said. “Hysterical statements—like calling people ‘traitors’ and ‘Uncle Toms’—really cheapened the power of ACT UP’s critique. ACT UP had really important things to say about gay leadership and its elitism, and it had important things to say about compromise and cooptation. But it wasn’t going to be heard if it was going to be saying outlandish things.” It was one thing to say gay leaders should be accountable, accessible, and democratic. But, said Vaid, “It’s another thing to say we shouldn’t have leadership, or to bully the leadership.”⁵³²

Larry Kramer agreed that ultimately ACT UP’s fatal flaw was its lack of, and hostility towards, leadership. By the time he and others realized things were out of control, Kramer said, “There was too much of an entrenched ‘democracy’ in place. This is a major problem of this [gay] community that we’re going to someday have to face: its inability to organize, to accept leadership, to respond to that kind of altogetherness”⁵³³

When it was good, ACT UP was very good, helping to accomplish tremendous results. Said Kramer, “Singlehandedly we changed the image of gay people from limp-wristed fairies to guerrilla warriors.” But then it became not so good. “It fell apart,” according to Kramer, “because it got out of hand, and there was no mechanism in any of the paperwork that allowed for getting rid of the crazies—and it became the haven for an

⁵³². Vaid interview.

⁵³³. Kramer interview.

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awful lot of crazies—and they managed to vote down a lot of stuff that should have been done.” Kramer said those who wouldn’t go along with the new agendas cobbled together from members’ personal priorities “went off and started other organizations, went to work for GMHC, or disappeared.”⁵³⁴

Or, as in the case of ACT UP’s Steve Michael, they became complete strangers to anything like rationality. Seeking to draw attention to AIDS, he said, Michael—now a one-man ACT UP/ Washington, D.C.—declared himself a candidate for president in 1996. David Smith, a spokesman for the Human Rights Campaign (the organization dropped the word “Fund” in an effort to downplay its connection to wealthy gay people and the mocking name of the “Human Rights Champagne Fund” as it was sometimes called by gay people), told Boston’s gay newspaper *Bay Windows*, “I think that his running for president is so ridiculous and so bizarre that it really can’t be dignified with any sort of rational comment.”⁵³⁵ Michael died from AIDS in 1998.

ACT UP/Golden Gate continued to be a respected source of information about treatment. ACT UP/San Francisco, on the other hand, insisted on perpetuating the protest group’s worst features, choosing to throw public and petulant tantrums rather than work for constructive change. In 1996, for example, a member of the group rushed the stage at a candidate forum in San Francisco, sponsored by the San Francisco AIDS Foundation, and threw twenty-five pounds of used cat litter at the forum moderator—none other than Pat Christian. The AIDS Foundation director said she would press charges against ACT UP. “It’s

⁵³⁴. Kramer interview.

⁵³⁵. Susan Ryan-Vollmar, “Ignoring the Skeptics, Activist Steve Michael Runs for President,” *Bay Windows* (19 October 1995), 3.

VICTORY DEFERRED

very important that we draw a very clear distinction between healthy debate and acts of violence,” she said.⁵³⁶

Other than a lone ACT UP member occasionally giving a provocative quote to a newspaper, or a flare-up of histrionics, the group by the mid-nineties was for all intents and purposes moribund, a toothless tiger. And what of ACT UP’s founder? What of the man described by his friends as privately soft-spoken and gentle, but who yelled and wrote loudly and angrily when he saw his friends dying while the rest of the world—including the gay community early on—didn’t seem to care?

When I interviewed him in March 1995, Kramer directed my attention to a thick manuscript sitting on a table amidst piles of packing boxes in his apartment on Washington Square—the site of the first-ever fundraiser for AIDS research, and where plans took shape for the world’s first AIDS service organization, GMHC. Kramer said the book he was working on would be his tell-all novel about the AIDS epidemic, and that it would be finished the day he dies. Sixty years old at the time, Kramer was living with HIV infection. And he was living with a man he loved, who loved him back, after so many years of wanting love. Not only did he seem to have found his bliss, but his partner, David Webster, was the man Kramer dated in the seventies and demonized as “Dinky,” the character in *Faggots* who rejects the monogamous love offered by the novel’s Kramer-like hero.

If the *New York Times* was to be believed, Kramer had indeed been domesticated. In a profile of him in January 1995 that included a photograph of Kramer cuddling with Webster, the *Times* itself seemed to wonder what to do after all the years

⁵³⁶. Wendy Johnson, “ACT UP Fouls Forum with Kitty Litter,” *Washington Blade* (8 November 1996), 14.

PART 6: ADVANCE AND RETREAT

of invective and op-ed columns “when a roaring lion learns to purr,” as the article’s title put it.⁵³⁷

Was it so? Kramer laughed as he recalled the angry letter he’d fired off the week before, criticizing the director of the Office of AIDS Research at the National Institutes of Health. “I faxed it to everybody—doctors, reporters, scientists, government officials,” he said. “I thought it was a very strong letter. I in essence called him an idiot, and asked him to resign.” But he quoted Victor Zonana [HHS Secretary Donna Shalala’s press secretary at the time] as saying, “Larry, it’s a very tame letter. You really have learned to purr.” Said Kramer, “I think you’re all used to me, in which case I’m not so effective anymore.”⁵³⁸

Some people may have gotten used to Kramer, but neither they nor the “crazies” who took over ACT UP were the reason why the protest group faltered. Their arguments had come to seem redundant after the government responded to their and the lobbyist’s demands, now spending billions of dollars on AIDS research and services. A president who professed to “feel their [and everyone else’s] pain took away a primary target. Most importantly, in the place of activists there were now thousands of AIDS organizations throughout the country—the AIDS “industry” made possible by the Ryan White CARE Act. Where once there had been lone voices, like Kramer’s, there now were publicity departments “spinning” the politics of AIDS in ways that protected their own interests and bottom lines. How the AIDS industry grew is a fascinating story of how the vision of a small number of dedicated people can make a tremendous difference in this world—particularly when they are backed by

⁵³⁷. Alex Witchel, “When a Roaring Lion Learns to Purr,” *New York Times* (12 January 1995), C1.

⁵³⁸. Kramer interview.

VICTORY DEFERRED

large sums of money. It's also the story of how too many visionaries were tripped up by their own myopia.

PART 7

INDUSTRIAL STRENGTH

Toil on heroes! toil well! handle the weapons well!

WALT WHITMAN, *AUTUMN RIVULETS*

Before there was an AIDS “industry,” there were concerned individuals who banded together to care for their friends and neighbors. As HIV spread, it became clear that a national “nerve center” was needed to link service providers with their counterparts in other areas of the country. Just as it was for people with AIDS, the sharing of “how-to” information among these organizations was vital to America’s response to the epidemic. Of course no one knew then that as the nationwide network grew stronger when the federal government finally funded it, it would also grow, like a kind of Frankenstein’s monster, into a massive creature that would turn on its creators. Those gay pioneers also didn’t know AIDS would last as long as it has done, or that the charitable services they once provided as volunteers would, with the 1990 Ryan White CARE Act’s billions, provide careers for thousands of AIDS “professionals.”

TWENTY-FOUR

During AIDS Action Council's first national meeting on AIDS politics, hosted by Paula Van Ness in Los Angeles the first weekend of October 1985, the executive directors of the country's largest AIDS service organizations (ASOs) decided they needed to form another national organization devoted exclusively to providing information and technical assistance to the groups sprouting up throughout the country. Van Ness, then director of AIDS Project Los Angeles (APLA), recalled, "Whenever someone started an AIDS organization they would hop on a plane or in a car and drive to one of the big AIDS organizations. They would either call or just show up at your door and say, 'I want to know everything you do.'"⁵³⁹ The older groups felt obliged to accommodate their visitors, but they were also trying to do their own jobs in the local community.

Although their initial idea was to incorporate the new organizations under the umbrella of AIDS Action Council, Gary MacDonald, then director of the council, said that ultimately they "didn't want a group that was associated with a political entity; they wanted basically a service group for their organizations."⁵⁴⁰ So three of the directors—Van Ness, Tim Wolfred from the San Francisco AIDS Foundation, and Richard Dunne from GMHC—invited the directors of the nation's other three largest ASOs—Larry Kessler from Boston's AIDS Action

⁵³⁹. Paula Van Ness, interview with author, Washington, DC, 25 April 1995.

⁵⁴⁰. Gary MacDonald, interview with author, Washington, DC, 7 February 1995.

VICTORY DEFERRED

Committee, Jim Graham from Washington, D.C.'s Whitman-Walker Clinic, and Bea Kalleigh from Seattle's Northwest AIDS Foundation—to join them in founding and funding the new organization. It would be known as the National AIDS Network (NAN).

NAN's rise and fall provides a dramatic illustration of how well-intentioned but inexperienced people tried to cope with an exploding epidemic and a nationwide network of community-based organizations struggling to do their best to replicate "mainstream" health and social services for people with AIDS who couldn't get those services in mainstream organizations. NAN's story also illustrates how gay social networks became lifelines connecting communities around the country and in the process creating an important component of the CARE Act when the federal government finally did something on a scale commensurate with its resources and the needs of Americans living and working with AIDS.

Paul Kawata was working for the city of Seattle in October 1985 when Richard Dunne called him and asked, "Do you want to go to Washington?" Looking back, Kawata said, "Being really stupid and really naïve, I said 'sure.'" Kawata flew to Los Angeles to meet with Dunne, Van Ness, and Wolfred. They all got along just fine. On Christmas Eve 1985, Van Ness called Kawata and asked how soon he could move from Washington State to Washington, DC So in January 1986, Kawata headed east to set up NAN's first office—above AIDS Action Council's office on Capitol Hill. NAN's founders pooled \$5,000 to begin the new organization. The newly dubbed executive director Kawata literally moved into NAN's office because he had no other place to stay at that point. And while the idea for NAN seemed clear to its founders, Kawata said it was much less clear to him what,

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exactly, he and NAN were to do. As he put it, NAN started out as “one guy, \$5,000, and a dream.”⁵⁴¹

Kawata could have been describing the experience of virtually everyone who ever started an AIDS organization. Without the benefit of years of experience—or even, necessarily, the awareness of existing organizations that could provide a blueprint of what to expect as their own fledgling agencies expanded—the growing AIDS organizations tended to lurch unsteadily forward as volunteers and what few staff there may have been tried as best they could to meet the growing demand for AIDS-related services.

Although there were people involved who had professional experience in health care and social services, many AIDS organizations, particularly in small towns, were run by people who tended to have more zeal than managerial experience. As John Paul Barnich said of his service on the board of AIDS Foundation Houston in the early eighties, “None of us had any experience at all at running a foundation. We were just a bunch of people who cared. We took care of people, we lost people, and we did the best we could.”⁵⁴²

NAN was dedicated to helping the new AIDS organizations, such as AIDS Foundation Houston, to do even better by teaching them to manage the business of providing AIDS services. Jim Graham, who became the treasurer of NAN’s board, told me that NAN’s goals were threefold: advocacy, providing technical assistance, and facilitating information exchange among

⁵⁴¹. Paul Akio Kawata, interview with author, Washington, DC, 24 March 1995.

⁵⁴². John Paul Barnich, telephone interview with author, 1 October 1995.

VICTORY DEFERRED

ASOs.⁵⁴³ These functions are what NAN cofounder Tim Wolfred described as “the self-help organizational development activities.”⁵⁴⁴

In October 1987, NAN cosponsored a meeting of 150 representatives from government and private sector organizations to map out a plan to address “AIDS into the Nineties,” as the meeting and report produced from it were titled. NAN was joined by the American Medical Association, the Association of State and Territorial Health Officers, and the CDC in producing this first-ever major collaboration among the various “players” involved in the nation’s overall response to the epidemic. Representatives of the federal government, ASOs, gay rights groups, the insurance industry, the Catholic Health Association, public health organizations, minority organizations, Burroughs Wellcome Co., and many others met together to discuss and argue about why America had faltered in its response to AIDS —and where, exactly, it ought to be going.

The group concluded that community-based ASOs were the backbone of the nation’s response but that those organizations needed to look to “a broader future when the AIDS response is concentrated within traditional mainstream organizations.” Coalitions, partnerships, and community alliances were viewed as essential to a fully mobilized national effort. Among the conference’s key outcomes was the recommendation that the new AIDS organizations develop strategic plans, more sophisticated fundraising efforts, collaborative partnerships with other main-

⁵⁴³. Jim Graham, interview with author, 29 March 1995.

⁵⁴⁴. Timothy Wolfred, telephone interview with author, 30 September 1995.

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stream groups—and, in effect, that they plan for an AIDS epidemic that would stretch into the foreseeable future.⁵⁴⁵

Peter Lee, who was hired as a consultant by NAN to produce the meeting and subsequently became NAN's program director, told me the conference "in some ways was the blueprint for the Ryan White CARE Act in terms of community control and the need to interrelate services and education."⁵⁴⁶ Just as the report was one of the earliest strategic assessments of the nation's AIDS response, the meeting itself was a prototype of the community planning councils mandated by the CARE Act to delineate services and distribute funding among local organizations.

In January 1988, I joined NAN's small staff as its publicist and staff writer. The agency's low-rent offices were connected to those of the Human Rights Campaign Fund (HRCF, now known as the Human Rights Campaign) in an old office building on Fourteenth Street NW, only a few blocks from the White House. The National Association of People with AIDS also shared space with us for a while. Our staff at that point consisted entirely of gay men and lesbians, and NAN offered me and a number of others the first taste we'd had of what it's like to be comfortably gay in a work environment.

My job entailed writing and editing NAN's newsletters, giving occasional interviews to the press, writing speeches for Paul Kawata, and, of course, doing whatever else might have need-

⁵⁴⁵. Michael E. Carbine and Peter Lee, *AIDS Into the 90s: Strategies for an Integrated Response to the AIDS Epidemic* (Washington, DC: National AIDS Network, 1988).

⁵⁴⁶. Peter X. Lee, telephone interview with author, 2 September 1995.

VICTORY DEFERRED

ed to be done around the office. NAN's biweekly newsletter *Network News* offered information about successful AIDS services in communities around the country, "how-to" stories that were told to us firsthand by the people who were pioneering AIDS services in America's big cities and small towns. We published articles on such topics as funding opportunities, AIDS informational hotlines, prevention campaigns, and the importance of having input from people with AIDS in the design of AIDS services, as mandated by the 1983 "Denver Principles." Above all, we wanted the information we provided to be practical and useful to the running of AIDS organizations.

Soon after my arrival at NAN, the organization embarked on a major binge of growth. The biggest boon to the two-year-old agency was its selection by the Ford Foundation in the spring of 1988 to house and administer the National Community AIDS Partnership (NCAP, now known as the National AIDS Fund), a unique matching-grants fund intended to support and expand community-based AIDS education and services. Directed by Paula Van Ness, NCAP was launched with an initial \$2 million grant from Ford, with another \$2 million expected to come from other national foundations and corporations, and an additional \$4 million to be matched with funds raised in local communities. NCAP funds, however, would not be distributed by NAN; rather, they were to be distributed by community foundations in the sites chosen by Ford.⁵⁴⁷

In keeping with its own name, NAN sought to network community-based AIDS groups with their counterparts throughout the country—making formal the informal networks that had been in place since the gay community first began to coalesce

⁵⁴⁷. John-Manuel Andriote, "NAN to House National Philanthropic Fund," *NAN Network News* (Washington, DC: National AIDS Network, 1 May 1988).

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nationally in the seventies, and which had proved so vitally important in the earliest years of the AIDS epidemic.

Many groups found all the technical assistance they hoped for in the *NAN Directory of AIDS Education and Service Organizations*, prepared by NAN staffer (today an HIV physician in San Francisco) Christopher S. Hall. For a mere five dollars cost to a member organization, the directory provided listings of local AIDS organizations, state AIDS coordinators, local public health agencies, key federal agencies, and national private-sector organizations addressing AIDS. Like the “coming out” experiences of the gay people who formed them, the new AIDS organizations were bolstered merely in knowing there were others like them working to provide AIDS services. The NAN directory was paid for with part of a \$125,000 contribution from New York-based Group W Television, which at the time was sponsoring a nationally syndicated series of documentaries, public service announcements, and feature-story segments called “AIDS Lifeline.”

NAN was selected by the CDC in the summer of 1988 to oversee a consortium of AIDS organizations that were tasked with developing model prevention programs targeting minority women. In keeping with its role as a provider of technical assistance, NAN’s part in the consortium was to develop informational materials based on the experiences garnered from three participating cities to assist ASOs in understanding and developing interventions specifically for women of color. In fact, NAN was one of the first national organizations to recognize the growing AIDS epidemic in communities of color and to try to address the needs of community-based organizations that were formed in the late eighties as the epidemic expanded among them.

VICTORY DEFERRED

Flush with a feeling of prosperity from its growing visibility and expanding coffers, NAN moved uptown into new offices across the street from CBS News in July 1988, after the staff returned from the annual gay and lesbian health conference, in Boston. Situated in the aptly named (in view of NAN's own expansion) Empire Building, NAN was reunited with AIDS Action Council, though only by virtue of their sharing contiguous offices. Jean McGuire, then the council's director, recalled, "I was very pissed off about the extent to which I was obligated to co-habitate, co-locate, and collaborate with the National AIDS Network."⁵⁴⁸ When there was discussion in 1989 of merging NAN and AIDS Action Council, McGuire protested, believing that NAN's image as a "gay" organization would be a hindrance to AIDS Action Council's just-emerging political clout in Washington.

To stoke and support the entrepreneurial spirit that pervaded NAN, more than seven hundred staff, board members, and volunteers from community-based AIDS organizations gathered in the Hotel Inter-Continental in New Orleans, October 20–23, 1988, for NAN's first management "Skills Building" conference. Sandi Feinblum, GMHC's first deputy director, organized the conference for NAN. Participants were offered presentations and workshops that dealt with the nitty-gritty of running professional organizations—including financial management, case management, fundraising and development, human resources management, public relations, and information systems. Robert A. Beck, the chairman emeritus of the Prudential Insurance Company—and father of Stephen Beck, who was then director of the National Association of People with AIDS—spoke in his plenary speech about the need for AIDS advocates to recog-

⁵⁴⁸. Jean McGuire, interview with author, Cambridge, Mass., 25 July 1995.

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nize that “the market is crowded with worthy causes competing for limited funds.”⁵⁴⁹

Encouraged by the success of the skills-building conference, NAN immediately began to plan a second conference, in Washington, DC, in November 1989, which would attract more than eight hundred participants. Only a few months after the New Orleans conference, though, strange things began to happen with NAN. On February 18, 1989, Paul Kawata announced that he would resign as NAN’s director. “The time has come to move on,” he said. “When you’ve been involved with AIDS as long as I have, it’s important to go on to new challenges within the epidemic.” In his three years at NAN, Kawata had increased the agency’s budget from its original \$5,000 to \$1.9 million and its staff from himself to twenty-one. GMHC’s Richard Dunne, chair of NAN’s board at the time, said, “All of us in AIDS are grateful for [Kawata’s] pioneering efforts.” Seattle activist Jim Holm—who was then cochair of the National Gay and Lesbian Task Force, and had moved from Seattle to Washington to be NAN’s director of administration and finance—was appointed acting executive director.⁵⁵⁰

By the time Kawata actually left NAN, on April 15, it was common knowledge that he’d been forced out by the board of directors because the organization had outgrown his ability to manage it. That same month I was laid off from my own job at NAN with the explanation that funding for my position had been cut. This was the first clue I had that NAN’s finances were far

⁵⁴⁹. National AIDS Network, *Conference Chronicle: The Publication of the 1988 NAN Skills Building Conference 2* (Washington, DC: National AIDS Network, 1988).

⁵⁵⁰. “NAN Executive Director to Move On.” News release from the National AIDS Network (18 February 1989).

VICTORY DEFERRED

less rosy than the agency's director and development department had painted them. Bill Freeman, who was hired in 1988 as NAN's first development director, said that he raised "about \$1.8 million" for NAN. But, he added, "Given the structure of the organization, it was a sinking ship."⁵⁵¹

In his role overseeing NAN's income and expenses, Holm recalled, "We kept getting more optimistic projections from [the development department] than were realized until we got ourselves into a very tight position." Holm said that there was jockeying for position between Kawata and Freeman, because Kawata had been accustomed to using his persuasive charm to raise money for NAN and had a hard time relinquishing the fundraising role to Freeman, a professional fundraiser.⁵⁵²

Even more taxing to the organization was the change of its board chairs. Richard Dunne stepped down on June 26, 1989, and on September 1 he resigned his position at GMHC, because he was himself struggling with AIDS (he died on December 29, 1990, at age forty-six). In his place came Richard Keeling, a physician who directed the University of Virginia's student health department and was board president of the American College Health Association—but who had no experience running a nonprofit organization, as Dunne had.

Beginning with Kawata's departure, NAN was rocked by a series of scandals that stunned AIDS activists and organizations throughout the country. In one way or another, they all stemmed from the organization's inept management—the very

⁵⁵¹. William J. Freeman, interview with author, Washington, DC, 13 February 1995.

⁵⁵². James Holm, telephone interview with author, 17 September 1995.

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thing NAN was created to alleviate in AIDS organizations. Bill Freeman left NAN in the summer of 1989, and the agency was unsuccessful in attracting another development director, at least partly because the board couldn't agree on just how NAN ought to raise money. Holm tried to implement an austerity program but the board resisted, wanting to hold out until a new director had been hired. His impossible job was to preside over the shrinking of an organization that had expanded too rapidly under Kawata's enthusiastic, albeit inexperienced leadership, amidst a growing epidemic, actually increasing funding for AIDS programs, and expanded demands for NAN's assistance as new organizations continued to form throughout the country.

After the board finally conducted a national search for a new executive director, Jim Holm seemed the candidate of choice. But a change of heart on the part of Keeling during the final round of interviews, in Chicago at the end of October 1989, ended Holm's—and every other—candidacy for the job. A member of the board's search committee, Eric Engstrom, director at the time of the Minnesota AIDS Project, suddenly expressed interest in the NAN position himself. As Jim Graham put it, "It was a highly unusual situation for a candidate to come from the search committee. I didn't know [Engstrom] was interested in the job." Holm said, "I knew something was very wrong. While I was enroute to the last interview, I was stopped in the hall by Rich Keeling, who informed me that he was not recommending me, but Eric Engstrom."

No one knew at the time that Engstrom and Keeling had become romantically involved. Keeling was ostensibly heterosexual, married to a woman. He and Engstrom denied that they were having an affair—although when Engstrom was fired by NAN's board only a few months later, Keeling's wife sued him for divorce and Engstrom decided to move to Charlottesville, Virginia, where Keeling lived. The two later moved together to

VICTORY DEFERRED

the Midwest. Holm was, to say the least, extremely angry about being passed over for Engstrom in view of the egregious conflict of interest that had propelled the Minnesotan into the director's chair.

As creditors barked outside NAN's doors, Engstrom's first move, according to Holm, was to deplete NAN's treasury by paying in full a \$60,000 bill for the 1989 skills-building conference. Holm had suggested structuring the debt, paying it off in installments, but was overruled by Engstrom. "All of a sudden," said Holm, "we didn't have money for payroll."⁵⁵³ In March 1990, NAN cut its already shrunken staff of seventeen by nearly a third. "We definitely have experienced revenue shortfalls since January," Engstrom understatedly told the *Washington Blade*. He reasoned that the \$40,000 he expected to save each month on five unfilled staff positions would suffice to replenish the depleted cash flow and hire a fundraising consultant. The problem was that no combination of any five salaries at low-paying NAN would have totaled that amount of money.⁵⁵⁴ Like NAN's development department, Engstrom was pulling figures out of the air.

Meanwhile, Engstrom and Keeling called upon foundations and large ASOs to try to bail out NAN. Holm said the pair "went to these foundations convinced that they were the team to save the AIDS effort in America." In a Minneapolis *Twin Cities Reader* article about "the rise and fall of AIDS activist Eric Engstrom,"

⁵⁵³. Ibid.

⁵⁵⁴. Julie Brienza, "National AIDS Network Hits Hard Times," *Washington Blade* (16 March 1990), 1.

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published six months after NAN board members told him not to disclose to contributors the extent of NAN's financial crisis.⁵⁵⁵

As late as April 1990, Engstrom optimistically assured NAN's few remaining staff that the organization would endure. He didn't tell them that he was borrowing money against the NCAP funds simply to make payroll, or that NAN was more than half a million dollars in debt. The money taken from the AIDS partnership funds technically belonged to NAN, but the fact was that the use of this money to meet NAN's operating expenses meant a diversion of funds that were intended for other purposes. In a fall 1990 article in the *Village Voice*, former GMHC director Rodger McFarlane referred to this as NAN's "fancy bookkeeping."⁵⁵⁶

NAN's board tried to put a positive spin on the situation, claiming in denial of the facts that the corporations and foundations that were contributing money to NAN and other AIDS organizations in increasing amounts were suddenly losing interest in AIDS. Engstrom warned that the federal government could not be counted on to increase funding for AIDS. Finally, on May 15, NAN laid off its last eight staff members, and officially suspended operations on May 24, 1990. "Financial troubles" were blamed for NAN's demise.

In a sad and bizarre ending of the organization that had helped volunteers to become AIDS professionals, some of

⁵⁵⁵. David Anger, ' " The End Was Chaos": The Rise and Fall of AIDS Activist Eric Engstrom,' *Twin Cities Reader* (13 November 1990), 6–9.

⁵⁵⁶. Rodger McFarlane, "Who's Driving the Bus? The Leadership Crisis in AIDS Service Organizations," *Village Voice* (4 September 1990), 18.

VICTORY DEFERRED

NAN's former staff donated their time as volunteers to assist in the agency's postmortem cleanup. After NAN closed, the *Chronicle of Philanthropy* noted, "In an ironic twist of fate, the national organization that helped hundreds of local AIDS groups raise money and manage their operations has shut down largely because it couldn't do either for itself."⁵⁵⁷

The dream that Paul Kawata and the six large AIDS organizations that initially backed him had seen materialize over the course of four and a half years had come to a troubled, troubling end. Kawata himself became executive director of the National Minority AIDS Council in 1990, a position he has retained for more than twenty years at this point.

Even as NAN weakened and died, another, far bigger, force was gathering steam in the Congress of the United States. In many ways it would continue NAN's own efforts to forge cooperation among organizations with vested interests in AIDS and support a community-based response to the epidemic. NAN's goal of putting control of AIDS services into the hands of people in local communities would live on in the Ryan White CARE Act —far bigger and better funded than anyone ever thought possible.

⁵⁵⁷. Elizabeth Greene, "A Worrisome Shutdown," *The Chronicle of Philanthropy* (10 July 1990), 17.

TWENTY-FIVE

In 1982, Pat Norman, the first director of the lesbian and gay health office in the San Francisco public health department, pulled together a group of five people to develop a plan (called simply the “San Francisco Plan”) that would steer people with AIDS to the services they needed from the moment they walked in the door to the very end of their lives, which in those days tended not to be a very long space of time.

If the individual was worried about possibly having AIDS—and of course no one in 1982 knew what caused AIDS, and the HIV antibody test was three years into the future, so no sexually active gay man in San Francisco at the time could be certain he would not develop the disease—he was sent to the Mission Health Center, in the middle of the Castro area. The Shanti Project (San Francisco) provided emotional support as well as housing, and the newly formed K.S. Foundation (now the San Francisco AIDS Foundation) offered supportive social services.

If the individual had Kaposi’s sarcoma, he’d be referred to Marcus Conant’s K.S. Clinic at the University of California–San Francisco. For *pneumocystis* pneumonia he’d be sent to San Francisco General Hospital. Looking back to that time when everyone was trying to figure out how best to deal with AIDS, Norman said, “We hadn’t been in an epidemic like this before. What book do you read in order to be able to do that? Now there are some books, but there weren’t before.”⁵⁵⁸

⁵⁵⁸. Pat Norman, telephone interview with author, 12 September 1995.

VICTORY DEFERRED

The organizations in San Francisco that were providing AIDS services in those early years were central components of what came to be known as the “San Francisco model” of AIDS care. That model, called a “continuum of care,” comprised a number of services typically provided by various community-based agencies that served to keep someone who had AIDS out of the hospital, living at home, and functioning as well and long as possible. These services included case management, hotlines, resource materials, workshops, attendant care, a “buddy” program to assist with practical needs, centralized or home-delivered meal services, ambulette services to get to medical appointments, a skilled nursing facility, a health-related facility that combines residential and care needs, hospice care, support groups and peer counseling, recreation or activity programs, legal services, financial advocacy, and group or scattered-site housing.⁵⁵⁹

In November 1985, the board of the Princeton, New Jersey-based Robert Wood Johnson Foundation (RWJ), the nation’s largest philanthropy devoted to health care issues, authorized a \$17.1 million AIDS Health Services Program to stimulate the development of community-based AIDS services throughout the country. Paul Jellinek, then RWJ’s vice president for programs, told me the foundation was unsure exactly how its money would be best spent. So they invited Dr. Philip R. Lee, then director of the Institute for Health Policy Studies at the University of California–San Francisco, and later the assistant secretary for health in the first Clinton administration, to meet with them in Princeton to talk about the San Francisco model of care.

“Phil described what happened in San Francisco,” said Jellinek. Lee told them that a combination of out-of-hospital,

⁵⁵⁹. Lewis Katoff, “Community-Based Services for People with AIDS,” *Primary Care* 19 (March 1992): 231–43.

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community-based support services and in-hospital treatment not only cost less than hospital treatment alone, but it was more in keeping with the needs and wishes of people with AIDS. Said Jellinek, “We saw that we could play an important role by helping others to learn about what had been done in San Francisco, and testing the viability of the San Francisco model in other communities that were beginning to see increased AIDS cases.”⁵⁶⁰

Besides having at least a hundred AIDS cases, the most important requirement for the cities that received funding from RWJ’s program was a willingness among medical, social service, and community-based organizations to cooperate in the development of systems of care.⁵⁶¹ In November 1986, RWJ made awards to nine projects serving eleven communities with the country’s highest AIDS caseloads—Atlanta, Dallas, Fort Lauderdale, Jersey City, Miami, Nassau County (N.Y.), Newark (N.J.), New Orleans, New York City, Seattle, and West Palm Beach.⁵⁶²

⁵⁶⁰. Paul Jellinek, telephone interview with author, 10 February 1995.

⁵⁶¹. Mervyn F. Silverman, M.D., “The Robert Wood Johnson Foundation AIDS Health Services Program.” In Vivian E. Fransen, ed., *Proceedings: AIDS Prevention and Services Workshop, February 15–16, 1990* (Princeton, N.J.: Robert Wood Johnson Foundation, June 1990), 37.

⁵⁶². Ruby P. Hearn, “An Overview of AIDS Programs Receiving Support from the Robert Wood Johnson Foundation,” in Fransen, *Proceedings*. Also Victoria D. Weisfield, ed., *AIDS Health Services at the Crossroads: Lessons for Community Care* (Princeton, NJ: Robert Wood Johnson Foundation, 1991).

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To help replicate the San Francisco model of coordinated AIDS care in its eleven pilot cities, RWJ hired some of the architects of the San Francisco model itself. Dr. Mervyn Silverman came onboard to direct the AIDS Health Services Program, bringing with him as deputy director Cliff Morrison, from San Francisco General Hospital. Known as a bridge-builder since his days in the Peace Corps, Silverman was at home with RWJ's efforts to stimulate cooperation among various health care and social service providers in the participating cities. "I've always believed in getting people to sit around a table and reach consensus if possible," said Silverman. "I did the same thing when I headed up the Robert Wood Johnson AIDS services program." He noted that often the different case providers would come "kicking and screaming" to the table, but that it was important "just to have people talking to each other, which quite often they don't do."⁵⁶³

Morrison's job with the program entailed visiting the participating cities to help coordinate their AIDS services. Morrison said that although RWJ originally intended to replicate the San Francisco model, it soon became clear that would not be fully possible in other cities because of social, political, and financial differences. Recognizing the limited extent to which San Francisco's model could be replicated elsewhere, the RWJ program revised its goal to simply build on a community's existing service structures and networks. Morrison recalled, "People would say, 'You can do these things in San Francisco that we can't do here.'"⁵⁶⁴

⁵⁶³. Mervyn F. Silverman, MD, telephone interview with author, 15 February 1995.

⁵⁶⁴. Cliff Morrison, telephone interview with author, 15 August 1995.

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Of course one of the biggest differences between San Francisco and virtually everywhere else in this country is the city's highly visible and politically influential gay community—with its many heterosexual supporters. Perhaps most importantly, the organizations that made up San Francisco's continuum of care—including the San Francisco AIDS Foundation, the Shanti AIDS Residence Program, the Visiting Nurses Association, and the AIDS unit at San Francisco General Hospital—were fortunate to have a large pool of volunteers to draw upon in the city's gay community. As early as 1984–85, volunteers in San Francisco had provided more than eighty thousand hours of AIDS-related social support and counseling services, responded to more than thirty thousand telephone inquiries and letters, and distributed nearly two hundred fifty thousand pieces of literature. Undergirding their efforts was an extremely supportive city government, which provided 62 percent of the funding needed by the volunteer-run service organizations, some \$7.4 million in fiscal 1984–85 alone.⁵⁶⁵

Until the RWJ program ended in March 1992, both Morrison and his boss, Silverman—as well as RWJ's national advisory committee, chaired by Phil Lee, and his successor, June Osborn, who also chaired the National Commission on AIDS under President George H.W. Bush—sought to keep the communities focused on one central thing, whatever their local efforts might be: the individual with HIV or AIDS. “We always had as our foundation the person afflicted with the disease,” said Sil-

⁵⁶⁵. Peter S. Arno, “The Nonprofit Sector's Response to the AIDS Epidemic: Community-based Services in San Francisco,” *American Journal of Public Health* 76 (1986): 1325–30.

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verman, “not how can we save money, how can we cut corners.”⁵⁶⁶

AID Atlanta was the only gay community-based AIDS service organization among the eleven RWJ sites to be selected as the program’s coordinating agency; in most of the other cities, the public health department administered the program. AID Atlanta’s main role was to provide case managers who coordinated services with other subcontractors in the city’s consortium of AIDS service providers. Grady Memorial Hospital, for example, provided HIV outpatient services as well as acute care services, and the Visiting Nurses Association coordinated home care for people with AIDS.

Jesse Peel, a retired psychiatrist who was on AID Atlanta’s board at the time, told me, “It was a distortion in some ways because we were the young, inexperienced organization that didn’t know how to do things—as opposed to the established entity [administering the RWJ program] in most cities. But it gave AID Atlanta a position of influence within the community. It gave us an enormous amount of leverage, especially with government funding, and a level of respectability we never would have had.”⁵⁶⁷

After selecting the sites for the RWJ program, the next step was planning strategically for what services would be needed, and who or which organization would best provide them. In developing its RWJ program plan, Bea Kalleigh said the city of Seattle, gay community in had an advantage in that service providers could look at and learn from the experiences of the

⁵⁶⁶. Silverman interview.

⁵⁶⁷. Jesse Peel, MD, telephone interview with author, 13 September 1995.

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first cities affected by AIDS. “It was clear by the mid-eighties,” she said, “that Seattle was more likely to follow the path of San Francisco [with AIDS cases mainly among gay men] than New York [with equally large numbers of cases among injection drug users]. I hate to call it an advantage, but that’s what made developing that kind of vision or plan easier for Seattle than it was for some of the first cities.”⁵⁶⁸

The third and most difficult step in implementing the RWJ program was getting local agencies to cooperate with one another. Even in Seattle, which became a model of cooperation, the agencies that became key components of the city’s early AIDS services network—Shanti Seattle, the Chicken Soup Brigade (which grew out of the Seattle Gay Clinic), the Seattle AIDS Support Group, and the Northwest AIDS Foundation—were initially competitive. But the Mayor’s Task Force on AIDS, established in 1983, made it clear there would be more than enough work for each organization. The former three-term mayor himself, Charles Royer, said in 1989, “The private non-profits must come to the city with a plan that shows how they are going to cooperate with other agencies, or they don’t get any money from the [city].”⁵⁶⁹ Fortunately, Seattle had a long history of cooperation between the gay community and the public health department, which helped to avert many of the problems faced by other cities where such a relationship didn’t exist.

In 1989, the federal Health Resources and Services Administration (HRSA) funded four demonstration projects—in Los Angeles, Miami, New York, and San Francisco—modeled di-

⁵⁶⁸. Bea Kalleigh, telephone interview with author, 5 October 1995.

⁵⁶⁹. Quoted in Weisfield, *AIDS Health Services at the Crossroads: Lessons for Community Care*.

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rectly after RWJ's AIDS Health Services Program. By providing public funding, HRSA hoped to stimulate existing nonprofit community-based organizations to develop a comprehensive out-of-hospital service delivery system for people with AIDS.⁵⁷⁰ Joseph P. O'Neill, a gay physician originally from San Francisco and long involved in caring for AIDS patients before becoming director of HRSA's HIV/AIDS Bureau—the bureau that oversees Ryan White CARE Act programs—described the HRSA demonstration projects as a “primordial” version of the CARE Act.⁵⁷¹

In fiscal 1991, the first year Ryan White funds were available, the nation's hardest-hit state, New York, received nearly \$63 million. By then, 42,548 AIDS cases had been reported in the state. The nation's second-hardest hit state, California, received a total of \$44.7 million under all the titles and programs for which the state was eligible in fiscal 1991. At that point, 38,437 people had been diagnosed with AIDS in the state since the start of the epidemic. By fiscal 1994, California had nearly tripled its CARE Act funding to just under \$123 million. In both California and New York—as in all other states receiving CARE Act funding—Title I cities and counties accounted for the bulk of the federal AIDS services funding that was being received. Together, the two states had received more than half a billion Title

⁵⁷⁰. Embry M. Howell, “The Role of Community-based Organizations in Responding to the AIDS Epidemic: Examples from the HRSA Service Demonstrations,” *Journal of Public Health* (Summer 1991): 165–74.

⁵⁷¹. From O'Neill's opening remarks to the Special Projects of National Significance “Objective Review Panels” review of grant proposals, at the Radisson-Barcelo Hotel, Washington, DC, 26 June 1996.

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1 dollars by the end of the CARE Act's first five-year funding cycle in 1995.⁵⁷²

Among the services paid for by CARE Act funding were primary medical care, substance abuse treatment, food and nutrition services, and medications. As with the RWJ community consortia—and harkening back to Pat Norman's AIDS Coordinating Committee even earlier—the CARE Act mandates that states and communities receiving AIDS-services funding must pull together “planning councils” to assess the local need and determine how the funding should be apportioned among service providers.

At the national level as well, HRSA has involved representatives of service organizations and people with AIDS—now referred to as “consumers”—in its planning processes. The AIDS program, now HRSA's single largest program, accounts for the bulk of its budget. Stephen Bowen, a physician and former CDC official who directed HRSA's HIV/AIDS Program Office (now the HIV/AIDS Bureau) from 1990 to 1995, told me, “We've really attempted to make programs be responsive to the needs of communities, their wishes, and have actively emphasized and encouraged the involvement of people with HIV as part of the planning councils, technical assistance, and program oversight.” In fact, said Bowen, a high percentage of HRSA's staff overseeing the CARE Act funding and recipients “are people who have been direct service providers.” He added that a “significant cadre” of openly gay people worked in HRSA's AIDS

⁵⁷². *HIV/AIDS Programs Expenditures and Accomplishments: FY91–FY95 State Profiles* (Rockville, Md.: Health Resources and Services Administration, May 1995).

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program and that the agency “actively recruit[s] HIV-positive people.”⁵⁷³

One of HRSA’s openly gay employees was Miguel Gomez, who started his AIDS career as the second employee of the AIDS Action Council, hired in 1985 by Gary MacDonald. After a few subsequent jobs working on AIDS issues—including three years at the National Council of la Raza, where he started an AIDS program for the nation’s largest national Hispanic organization—Gomez was hired by HRSA to be one of its key spokespersons for the CARE Act programs. Reflecting on the CARE Act’s debt to—and differences from—the original San Francisco model developed largely by gay people, Gomez told me that in the CARE Act the federal government was interested in replicating the model of integrated community-based services, rather than the particular services or organizations in San Francisco *per se*.⁵⁷⁴

Besides bolstering the already existing AIDS service organizations throughout the country, the availability of so much money under the CARE Act on a competitive basis brought many people and agencies that had never before been involved with—or necessarily even interested in—providing AIDS services to the AIDS “industry.” By the mid-nineties, an estimated eighteen thousand organizations throughout the country were providing some kind of AIDS-related services—some 200 different agencies in San Francisco alone.

⁵⁷³. Stephen Bowen, MD, telephone interview with author, 5 July 1995.

⁵⁷⁴. Miguel Gomez, interview with author, Washington, DC, 13 April 1995.

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How and why did all these organizations appear? Paul Kawata, who directed the National AIDS Network before becoming the executive director of the National Minority AIDS Council, echoed what I've heard from others: "There was so much rage and anger," he said. "And it felt like there was a lot of dollars. So if you weren't going to meet my needs, I'll go off and start my own organization."⁵⁷⁵ Anger and large amounts of CARE Act money fueled a lot of activists—and a hell of a lot of AIDS organizations.

I asked Joe O'Neill, just before he became director of the HRSA HIV/AIDS Bureau in 1995, whether the country could sustain the multitude of AIDS service providers drawing down CARE Act funding. "You can't," he said, "at least not on the public dole." As an example he referred to the extraordinary number of agencies providing AIDS services in San Francisco. "We can't pay two hundred executive directors out of Ryan White money," he said. To continue getting Congress's support of the CARE Act—which was in doubt between the time of its expiration in 1995 and much-delayed reauthorization in 1996, and has continued to raise doubts each time it comes up for renewal—O'Neill foresaw a coming time of "painful discussions" of consolidation. "I'm not referring to the care and maintenance of organizations," he said. "I'm referring to the care and maintenance of sick individuals."⁵⁷⁶

No one who participated in Pat Norman's AIDS Coordinating Committee back in 1982, the NAN "AIDS Into the Nineties" conference in 1987, the Robert Wood Johnson Foundation pilot projects, or the HRSA demonstration projects in the late eight-

⁵⁷⁵. Kawata interview.

⁵⁷⁶. Joseph P. O'Neill, MD, interview with author, Washington, D.C., 29 August 1995.

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ies, could have guessed how far-reaching their vision for AIDS services would prove to be. As they depended upon the kindness and donations of friends and strangers alike, those pioneers could only dream of something like a CARE Act. They never dreamed there would be so fantastically much money for AIDS services, or that so many organizations would become interested in providing them.

Nor could they have foreseen that there would often be so much ill will among AIDS “industry” advocates in Washington as they fought with one another for the biggest piece of the federal money pie they could possibly get. And how could they possibly have known the AIDS industry would “de-gay” itself, denying the proud heritage of the gay people who were its pioneers? Then again, the de-gaying of AIDS by the Washington lobbyists representing the AIDS industry had brought about the CARE Act in the first place.

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Representatives of the AIDS “industry” spoke regularly of the needs—at least the needs as they were defined by the service organizations—of so-called “special populations.” Strangely, somewhere in the discussions of what people with AIDS need, gay men no longer were considered a “special population.” One could sit, as I have done, in meetings with AIDS advocates who speak of every possible type of person affected by HIV—women and children foremost among them, followed by people of color, substance abusers, the homeless—and not hear the words “gay men” come up even once. You might wonder, as I have done, when gay men, whatever their race, had supposedly overcome America’s antigay bigotry, effectively prevented new infections, and received all the AIDS services they might need.

You might wonder as well why the advocates weren’t talking about gay men when we continue to account for the majority of AIDS cases and new HIV infections in most of the United States. Before the CARE Act, gay lobbyists in Washington, to win support and funding, encouraged politicians to feel good about doing something for the women and children, eagerly downplaying the vast numbers of gay men afflicted by HIV and AIDS. Now AIDS service providers themselves championed people with AIDS who were poor, female, ideally prepubescent (“innocent victims,” they were called)—and definitely not white or gay.

As AIDS advocates pushed and pulled Congress in 1995 to reauthorize the Ryan White CARE Act for another five years, the internecine squabbling among them spilled onto the pages

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of the Washington Blade. Which was ironic given the insistence by AIDS Action Council and other advocates that they were foremost “AIDS” and not “gay” organizations. Clearly when they needed their moral support boosted, they turned to the community that created and stood with them no matter how often they chose to push aside the needs of gay men. What became starkly clear to those outside the inbred world of AIDS advocacy was that AIDS had become a big business. It was also apparent that those who lobby the federal government for AIDS funding speak of the “needs of people with AIDS” as though they are necessarily and always the same as the needs of their own particular organizations.

AIDS had become a special interest in the truest sense. And the advocates were interested in keeping AIDS as special as possible. Doing so ensured that the CARE Act’s hundreds of millions of dollars would continue to flow to the legions of AIDS organizations, pay checks would be processed on time, and expense accounts would ensure the globe-trotting advocates’ continued enjoyment of their favorite hotels and restaurants. The days were past when activists slept on one another’s floors and couches to save money, and signed onto the “cause” because they were angry and committed. AIDS had become a career that offered perks, travel to interesting places, and the righteous sense that one was doing “God’s work.” Jean McGuire’s vision of AIDS organizations putting themselves out of business by incorporating AIDS services into mainstream health and social welfare organizations seemed shortsighted; she hadn’t foreseen the way the millions from the CARE Act would spawn a now self-perpetuating “industry.”

The public battles among the lobbyists revealed just how far the AIDS industry had come since Gary MacDonald *was* AIDS Action Council and the only full-time AIDS lobbyist in Washington. The battles made it apparent that besides the traditional

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enemies of the AIDS “movement”—including price-gouging pharmaceutical companies and the federal government’s lethargy—there was another enemy even closer to home. This enemy, dividing and coming perilously close to conquering the AIDS advocates themselves, was something as old and tainted as politics itself: greed and the lust for power.

Advocates used their respective versions of the “needs of people with AIDS” as bludgeons against one another for daring to disagree over political strategy in their joint, and frequently disjointed, efforts to get the CARE Act reauthorized by a Congress now controlled by Republicans. The Act’s two most heavily funded sections were Title I, designed to provide funding assistance to the hardest-hit metropolitan areas, based on their cumulative AIDS cases since the start of the epidemic, and Title II, which provided grants to the states for AIDS services.

In 1995, AIDS Action Council supported a new appropriation process being considered in the Senate that would have jointly funded AIDS services in cities and states, rather than separately as had been done in the CARE Act’s first five years. The council touted this single appropriation as a way to address the growing numbers of AIDS cases outside the cities that were the first, and still hardest, hit by the epidemic. Other advocates, however, wanted to retain the original funding formula, fearing that a single appropriation would take money away from the hard-hit cities where most people with AIDS live, and would give a disproportionate amount of funding to rural areas and smaller towns.

Mark Barnes, then the executive director of AIDS Action Council, wrote in the *Washington Blade* in April 1995, “For the past several years, cities and states have lobbied separately for appropriations of funds under Title I and II...What if, instead of lobbying separately for their own funds, the cities and states

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would need to lobby together for a common pot of money, so that each dollar won would be of benefit to PWAs in both cities and states?”⁵⁷⁷

Ernest Hopkins, a Black gay man affiliated with a group called the Cities Advocating for Emergency AIDS Relief (CAEAR) Coalition, responded for the “other side.” The coalition was formed in 1991 to lobby for increases in Ryan White funding for the nation’s forty-nine eligible Title I metropolitan areas. Its supporters included the National Association of People with AIDS, Mobilization Against AIDS, and the National Task Force on AIDS Prevention. In an opinion article in the *Blade* a week after Barnes’s own article, Hopkins wrote, “If changes in the funding formula shift money from urban to rural areas, and the pooling of funds for Title I and II leave urban areas vulnerable to further shifts in funds, a disproportionate number of those who will suffer will be those who depend on federal funds the most: the urban poor, including high percentages of minorities.”⁵⁷⁸

Pat Christen, the nongay director of the San Francisco AIDS Foundation at the time, had been one of the people who masterminded the legislation that became the Ryan White CARE Act as a way to provide “disaster relief” to hard-hit cities like San Francisco. But in June 1995 Christen resigned from AIDS Action Council’s board, after serving on it for eight years, because she believed the council’s support of the single appropriation measure would be harmful to her organization. In her seven-page resignation letter, Christen wrote that “the Council

⁵⁷⁷. Mark Barnes, “Cooperation Needed to Pass Ryan White Bill,” *Washington Blade* (14 April 1995), 45.

⁵⁷⁸. Ernest Hopkins, “Sound Strategy Needed to Pass Ryan White Bill,” *Washington Blade* (21 April 1995), 43.

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is advocating for a position that literally takes desperately needed resources away from people with AIDS in one community in order to give those resources to people with AIDS in another community.”⁵⁷⁹ Christen told me in an interview, “I felt that in good conscience I couldn’t sign a \$70,000 check over to an entity that in the end, were their positions to be implemented, would harm the city of San Francisco.”⁵⁸⁰

On a political level, it wasn’t surprising that the executive director of San Francisco’s leading AIDS organization would see the interests of her agency, the city, and people with AIDS as one and the same; in the game of politics, as Chai Feldblum put it, winning as much as possible is what it’s all about. To some, however, the single appropriation that AIDS Action Council supported seemed to be a reasonable attempt to address the changing demographics of the epidemic and to loosen the grip that cities like San Francisco had on CARE Act funding because of their big caseloads and big, influential AIDS organizations.

As reasonable and fair as it might have seemed to those supporting it, the manner in which the council came to endorse the single appropriation concept raised serious questions about its own ability to see the interests of people with AIDS as being sometimes different from its own interests or those of its member organizations. The chair of AIDS Action Council’s policy committee, Doug Nelson, was also the head of a group called the Campaign for Fairness. The campaign’s goal was to increase federal funding for AIDS organizations in rural areas that

⁵⁷⁹. José Zuniga, “Departure Signals Rift in Ranks at AIDS Groups,” *Washington Blade* (23 June 1995), 1.

⁵⁸⁰. Pat Christen, telephone interview with author, 20 September 1995.

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felt “ripped off” because they were receiving less under the CARE Act than the cities that had tens of thousands of AIDS cases. For Nelson, it seemed a classic Robin Hood scenario: take from the rich, give to the poor. As he saw it, the “poor” naturally included the AIDS Resource Center of Wisconsin, of which he was executive director.

Nelson was able to use his influential position within AIDS Action Council to push his agenda, the single appropriation idea, under the rubric of “fairness.” As director of an AIDS organization in Milwaukee, a second-tier city, Nelson’s self-interest in advocating to change the CARE Act funding formula threatened to split the national AIDS advocacy coalition down the middle. To add further weight to what he and a number of others viewed as a supremely moral crusade, Nelson’s Campaign hired former AIDS Action Council director Dan Bross—by then employed in a lobbying firm run by two former members of Congress, both Republicans—to push the funding formula changes on Capitol Hill. No one, except Pat Christen, seemed to see a conflict of interest in Nelson’s simultaneously chairing the policy committee and steering AIDS Action Council, and the public debate, toward advocating a position which benefited the organization that paid his salary.

The Campaign for Fairness wasn’t the only group to hire former AIDS Action Council staff to represent their special interests. Tom Sheridan left AIDS Action Council in late 1990—not long after the Ryan White CARE Act that he was so instrumental in passing was signed into law, and not long after Jean McGuire left Washington because, as she saw it, the window of political opportunity on AIDS had closed. Sheridan formed a lobbying firm called the Sheridan Group, and in 1993 he formed the AIDS Political Action Committee to try to win favor among politicians the old-fashioned way: by donating money to their campaigns.

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Like other AIDS advocates in Washington in 1995, Sheridan lobbied for reauthorization of the CARE Act—on behalf of the San Francisco AIDS Foundation, as well as for Ernest Hopkins' own CAEAR coalition, listed respectively as numbers 1 and 2 on the Sheridan Group's list of clients. Pat Christen had become a member of the honorary board of AIDS-PAC. "All the executive directors from the major AIDS organizations are on the honorary board," Sheridan told me.⁵⁸¹ Not unexpectedly, they strongly opposed the single appropriation being advocated by AIDS Action Council.

When the CARE Act was finally reauthorized, in May 1996, through fiscal year 2000, it seemed the best that could be said for the AIDS advocates who lobbied for it was that they had united to resist the cuts in funding that were rumored to be in the works by hostile Republicans. The rifts among them had been revealed for what they truly were: competing organizational interests, frequently masked in rhetoric about the "needs of people with AIDS." In actual fact, they spoke on their own behalf, which sometimes included the interests of people with AIDS, but at other times seemed to have much more to do with their board members' personal priorities and the expectations of their now-large staffs to be paid on a regular basis.

At the height of the acrimony and jockeying for position among the lobbyists on the CARE Act reauthorization, Cornelius Baker, then policy director of the National Association of People with AIDS, told the Blade that he couldn't think of another instance in which AIDS advocates had experienced "even half the amount of rancor as the one involving Ryan White

⁵⁸¹. Thomas Sheridan, interview with author, Washington, DC, 24 February 1995.

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reauthorization.” Then again, Baker added, “none have had this amount of money attached to them.”⁵⁸²

No one could deny that services for people with AIDS were vitally important. But an informed observer had to question why the AIDS lobbyists focused exclusively and tenaciously—ripping one another to shreds, if necessary, in the process—on services funding. They had never managed to find the same level of passion for mounting a major push to get the federal government to pay for prevention campaigns that were relevant to real people’s lives. Might it have had something to do with the fact that funding cuts would mean that they’d have to find a way to collaborate so that perhaps one or a few organizations could serve multiple populations—rather than there being a different organization for every possible variation on the theme of personal identity? Or, more to the point, might it mean that their own organizations, paychecks, and perks would have to be scaled back?

From where he sat in Dianne Feinstein’s office in the US Senate, Ralph Payne, then the senator’s staffer for gay and AIDS issues, told me in late 1995 that the many AIDS advocates who called upon him had never talked, for example, about AIDS research. On the other hand, he estimated that he probably attended 100 meetings about the Ryan White CARE Act. Payne said that while the activists were “blackening the sky with planes” to fly into Washington “to argue about minutiae and funding formulas in the Ryan White CARE Act,” none of them seemed interested in other federal entitlement programs that provide support to people with AIDS, such as welfare and Medicaid. Yet in his home state alone, he said, “There’s as much money flowing into California Medicaid dollars as in all

⁵⁸². José Zuniga, “Departure Signals Rift in Ranks at AIDS Groups.”

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Ryan White dollars; Medicaid is by far the biggest AIDS program in the country.”⁵⁸³

In fact, 40 percent of people with AIDS in the United States ended up on Medicaid as their sole means of support, according to Tim Westmoreland, who was director of the federal Medicaid program from 1999 to 2001. Until Medicare Part D in 2006 began to cover the cost of medications for people with HIV/AIDS on Medicaid, the Medicaid program was the largest source of federal HIV funding.⁵⁸⁴ “Ryan White is a drop in the bucket compared to Medicaid,” said Westmoreland. Long familiar with the priorities of AIDS advocates from his years of being lobbied by them while he worked in the House of Representatives, Westmoreland cautioned, “If we fail to defend Medicaid, we will be doing a tremendous disservice to people with AIDS.”⁵⁸⁵

Once it seemed the CARE Act would be reauthorized, AIDS advocates did turn their attention, at least partially, to Medicaid. In October 1995, AIDS Action Council director Barnes wrote in the *Blade*, “While Ryan White provides more than \$600 million a year to cities and states hardest hit by AIDS, *more than \$3 billion* [my emphasis] in Medicaid funds are being spent annually on medical services for the poorest and sickest people with

⁵⁸³. Ralph Payne, interview with author, Washington, D.C., 24 September 1995.

⁵⁸⁴. Kaiser Family Foundation. (Fact sheet) *Medicaid and HIV/AIDS* (February 2009), at http://www.kff.org/hivaids/upload/7172_04.pdf, accessed 29 June 2010.

⁵⁸⁵. Westmoreland made these remarks during a 14 February 1995 breakfast “roundtable” at the offices of the National Gay and Lesbian Task Force (NGLTF), in Washington, DC

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HIV disease. In its role as a safety net, the Medicaid program finances clinic, hospital, and nursing-home care and lifesaving AIDS drugs for more than half of the Americans living with HIV disease.”⁵⁸⁶

Since the survival of so many people with AIDS was quite literally at stake in the debates over Medicaid reform, one might reasonably ask why AIDS advocates were so late in focusing on the federal/state entitlement program. After all, they claimed that the “needs of people with AIDS” were their first priority. Could it have had something to do with the fact that Medicaid provides health care for individuals—and doesn’t put money into the coffers of AIDS service organizations? As Ralph Payne observed, “The lobbying becomes about increasing funding for the organizations, and has very little to do with people who need the services, very little to do with ending the epidemic.”⁵⁸⁷

But there was something else at work, too. The years spent building the country’s AIDS services infrastructure were years when the goal of AIDS lobbyists in Washington was to win as much as they could for AIDS alone, with little regard for people with other diseases or whose financial precariousness left them as dependent upon the government as many people with AIDS were. Reflecting upon the “exceptionalism” that underlies federally funded programs like the Ryan White CARE Act, Jean McGuire said, “I was deeply disturbed by difficulties we had having any kind of conversation about what did it mean in the Medicaid program I worked on so long to create different levels of access relative to the particular disease you have. What did

⁵⁸⁶. Mark Barnes, “Medicaid Proposal Spells Out Deadly Reform,” *Washington Blade* (13 October 1995), 33.

⁵⁸⁷. Payne interview.

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it mean to say this particular disease elevates the status of your poverty over someone else's poverty?"⁵⁸⁸

McGuire said that AIDS advocates resisted framing the struggle for protection from discrimination and against utter destitution in a broader "poverty discourse"—what it means to be both sick and poor in the wealthiest nation in history—because they view the broader systemic reforms that are so clearly needed in the nation's health and social welfare programs as beyond either the scope of their concern for AIDS or their ability to effect change. Yet, as McGuire pointed out, one can't really talk about AIDS without talking about issues of poverty, disenfranchisement, and the cracks in the nation's social welfare infrastructure that can swallow someone who is sick and poor. The more thoughtful leaders in the gay rights movement have said similar things about how the struggle for equal rights for gay men and lesbians is ultimately about the struggle for the dignity and freedom of all people.

Jane Silver, then public policy director for the American Foundation for AIDS Research, told me in 1995, "AIDS is a prism by which to look at all that's wrong with the social welfare system." For AIDS advocates, though, Silver said it's a question of whether to take their pot of money and run, or to work toward broader reform that will benefit people with AIDS as well as people with other compelling medical needs. She said, "It becomes a question of, do you take on the welfare system, and the social service system? Or do you carve out AIDS-specific services? It's the same dilemma of how much can AIDS advocates fix, and how."⁵⁸⁹

⁵⁸⁸. McGuire interview.

⁵⁸⁹. Jane Silver, interview with author, Washington, DC, 13 March 1995.

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Before AIDS forced young white middle-class gay people to confront both mortality and the inequities of America's social welfare system, they, like most white middle-class people, didn't think much about programs like Medicaid or welfare. But they were outraged and appalled when they saw professionally successful, sometimes affluent, gay men lose their jobs, their homes, and be forced to spend themselves into poverty in order to be eligible for federal assistance to pay for exorbitantly priced AIDS treatments and to get from gay community organizations the services they couldn't receive from mainstream health and social service providers. AIDS advocates successfully persuaded the federal government to fund special programs for people with AIDS under the CARE Act. But as the epidemic continued to spread among nongay, nonwhite, non-middle-class people, their arguments began to seem short-sighted, even selfish. What they wound up with was a parallel system of services created specially for AIDS, even as people who were poor and sick with the "wrong" disease (that is, not AIDS) continued to struggle with inadequate health care and social welfare programs.

One might reasonably expect that an important lesson from the gay community's experience with AIDS would be a recognition of the fact that everyone who is in need is equally deserving of assistance and support. But by the mid-nineties AIDS advocacy had gone well beyond the gay community that initiated it. AIDS service organizations now constituted an industry whose lobbyists in Washington work to make sure their employers get all they can. They played up or played down whichever subpopulation of people with AIDS suited their needs of the moment. If they were speaking to members of Congress, women and kids were still a sure bet to win support. If they were speaking to a group of gay people—who were still good for very generous donations—they might actually acknowledge

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that gay men continued to bear the overwhelming brunt of the epidemic in this country. As with the seasoned lobbyists in the heyday of the NORA coalition, whatever it took to win is what they did.

They played within a system that rewards those with political and financial resources, even as those who lack them are forced to languish without a CARE Act to meet their particular needs. They talked a good line about race and poverty and all the “isms” and “phobias” that, for them, neatly explained the AIDS epidemic and the nation’s response to it. But they didn’t ask the most obvious questions: Why should AIDS services now get more than \$2 billion a year under the nation’s only disease-specific funding measure? Is it because of the disease’s infectiousness? Or because of the young age and productive years lost of its victims? Those are certainly compelling reasons to make AIDS a top priority.

One final question, though, was avoided because of the discomfiting implications of its answer: Was AIDS an “exception” because of the political and financial resources of the AIDS industry, and because the CARE Act was now the largest budget item at the Health Resources and Services Administration, the biggest funder of the AIDS industry, and every bit as invested as the advocates in continuing the CARE Act?

Perhaps such questions would be sorted out and answered in time. For the moment, AIDS advocates continued fighting to keep their own piece of the pie, arguing that AIDS was exceptional and should continue to be treated as such by the federal government. “We may still be too scared to ask those questions,” said Jean McGuire. “They are ultimately about giving up privilege.”⁵⁹⁰

⁵⁹⁰. McGuire interview.

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TWENTY-SEVEN

“This is like the campaign that has no election day,” said Tom McNaught, the communications director for Boston’s AIDS Action Committee at the time of our 1995 interview. McNaught had seen his share of political campaigns as a staffer for the late openly gay US Representative Gerry Studds (D-Mass.). But the campaign against AIDS was different from any McNaught had experienced before, and its interminableness was wearing on him. “I sometimes feel guilty,” he said, “that I can’t sustain the energy level I had when I was putting in seventy-hour weeks, coming in on weekends, and chewing Nicorette gum like it was going out of style.” He asked, “How many rallies, how many national debates, how many get-out-the-votes, and how many clever efforts that you’d do in a campaign can you do when you don’t even have an election date?”⁵⁹¹

By the time I interviewed McNaught and his boss in 1995, Larry Kessler, the executive director of AIDS Action Committee, had been at the organization’s helm since its January 1983 inception. I asked Kessler whether he expected still to be doing in the mid-nineties what he was doing in the early eighties. “No,” he said, without hesitation. “We originally thought we’d be out of existence in three years, that this was very short-term, there’d be a cure and treatment would be quick.”

Those expectations obviously needed to be revised as a cure and even effective treatments proved to be elusive. “By the fifth year,” he said, “we started thinking more in ten-year

⁵⁹¹. Thomas McNaught, interview with author, Boston, 24 July 1995.

VICTORY DEFERRED

terms. In the tenth year, we started thinking in twenty to twenty-five year terms.” The agency had just leased space for a thrift shop to help diversify its income. “We signed a ten-year lease that goes until the year 2005,” said Kessler. “Now it seems like that’s not enough.”⁵⁹² Boomerangs, AIDS Action Committee’s thrift store in Boston’s Jamaica Plain section, was still open when I went back to do interviews in 2010.

AIDS Action Committee was unusually fortunate to have a leader like Kessler, who brought with him not only many years of experience as a community activist, but also a willingness and ability to go with and manage the flow of organizational growth spurred by a burgeoning epidemic and, at least in the nineties, vastly increased financial resources. More typically, AIDS organizations that were born and reared in the early to mid-eighties experienced sometimes wrenching growing pains as they evolved from the jury-rigged volunteer organizations that sprang up in the epidemic’s early years, into professionally run community institutions often with annual budgets now in the millions of dollars.

For most AIDS groups, the focus on the short term stemmed from the faith of virtually everyone in the early years that there would be a cure within a relatively short period of time. At the San Francisco AIDS Foundation, for example, former communications director Joe Fera said the agency had been reluctant to plan for the future. “We thought long-range planning implied that we have to be there a long time,” he explained. “Our hope was that we would not be here in five years, or that in five years we would be dealing with a mop-up situation. And that has not

⁵⁹². Larry Kessler, interview with author, Boston, 24 July 1995.

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proven to be the case.”⁵⁹³ In Chicago, Eileen Durkin, director of the Howard Brown Memorial Clinic at the time of our interview, said, “The fact that it’s no longer ‘until the cure,’ but is now a permanent issue and a permanent disease, brings about a whole different set of responses and frustrations.”⁵⁹⁴

Karl Mathiasen III founded the Washington, D.C.-based Management Assistance Group to aid progressive nonprofit organizations with the business aspects of their operations. In the mid-nineties, the group’s clients included virtually all of the nation’s largest AIDS organizations. Mathiasen was seen as something of a guru among the leaders of those organizations. Beginning with the National AIDS Network’s first 1988 “Skills Building Conference,” in New Orleans, Mathiasen regularly presented workshops on “the organizational life cycle” for AIDS service organizations.

As Mathiasen saw it, AIDS service organizations began as the campaign-like groups that Tom McNaught and thousands of others who ran and provided services through them expected them to be. But unlike political campaign organizations—dedicated to the specific, short-term goal of beating an opponent—the AIDS groups were faced with the prospect of a far longer and more arduous campaign than anyone imagined in the first few years of the epidemic. When it became evident that the campaign against AIDS was going to require a long-term commitment, it became equally apparent that the organizations created to serve those affected by HIV were going to have to shape up if they were going to hold their place on the frontline of this particular war.

⁵⁹³. Joseph Fera, interview with author, San Francisco, 30 January 1995.

⁵⁹⁴. Eileen Durkin, interview with author, Chicago, 1 June 1995.

VICTORY DEFERRED

Mathiasen said, "We knew halfway through the eighties that this was not a campaign and the organizations had to settle down and create appropriate boards and set up systems." All organizations resist systems, he said, and this was particularly true with ASOs. "Part of the reason," he explained, "was resistance to bureaucracy and institutionalization, which was unattractive to AIDS activists who had felt put down by institutions in their lives before. He added that besides the usual nonprofit resistance to "shaping up," there was a fear of "creating monster organizations of the kind that are going to reject us." Although he didn't use the term, Mathiasen described the "internalized homophobia" that gay people working in ASOs often turned upon one another and upon the organizations themselves. "Part of the reverberations and problems within ASOs is a result of gay politics," he said. "There's a lot of anger, a lot of putting other people down that seems to enter into the organization more thoroughly than in other organizations."

In particular, said Mathiasen, the leaders of AIDS organizations are favorite targets for this projected self-hatred. He illustrated his point by recalling the demise of the National AIDS Network. "When NAN folded," he said, "and some of the leaders were dismissed, it wasn't that they were dismissed as leaders. They were first not acknowledged as having been leaders, and were dismissed as not doing the right job without an acknowledgement that they were probably the right person for the job when it began." Not only was their work unacknowledged, but they were dismissed as people. Said Mathiasen, "They were banished in a way, put down, depersonalized. You were not only a bad leader, you were a bad person." he added, "That infuriated me."

On his first visit to GMHC, Mathiasen said he was fascinated by the "family atmosphere" of the organization. "ASOs cre-

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ated a sense of family for gay men in particular who did not have that," he said, "a place where they could be free about their sexual orientation, where they could be demonstrative." But Mathiasen believed that some of the family feeling had to give way to the need for efficient and stable organizations, the lines drawn more clearly between the personal and professional. Bureaucratizing, institutionalizing—the business of running a business—"was really necessary for the work that had to be done," said Mathiasen. "Even if it wasn't a campaign, the business of getting organized was unattractive business. Some people got it and some people never did. People forced out felt they'd lost their families as well as their jobs."

One of the unique challenges for AIDS organizations has been what Mathiasen described as their "telescoped growth." They have grown, sometimes explosively, because of both the burgeoning epidemic, and because of the increased availability of funding, particularly through the CARE act. This has meant, said Mathiasen, that "things that took three or four years in other organizations had to be done in six to eighteen months."⁵⁹⁵

Torie Osborn, who was executive director of the Los Angeles Gay and Lesbian Center for four years, understands the need for gay and AIDS organizations to be professionally run. Osborn, who holds an MBA, noted that virtually all advocacy organizations in this country start out as volunteer groups before becoming "professional." "The only thing different about AIDS," she said, "is the impact of gay culture on the organizations, and the fact that because the epidemic has moved so quickly, and we've had to do the government's work for them, the growth has been compressed into a shorter period of time. Other than that, guys, we ain't no different from anybody else."

⁵⁹⁵. Karl Mathiasen, III, interview with author, Washington, DC, 4 April 1995.

VICTORY DEFERRED

Every Chinese community center, every YMCA, every nonprofit organization in this country started out as a small grassroots group.” She added, “We’ve created an AIDS industry. How the hell else could we do it? You can’t just keep running these [ASOs] out of your living room forever.”⁵⁹⁶

Former GMHC director Tim Sweeney told me that the “industrialization” of AIDS was a good thing. “I can tell you I ran the biggest AIDS organization in America,” he said. “I needed better management skills. I was in over my head at times and it was very frustrating.” He added, “That’s why I’m frustrated when people say that AIDS has become an industry. I almost want to say, ‘Thank God,’ if that implies experience, if that implies people who have taken risks, failed, and learned from them. I think that’s okay. We’re not innately intelligent about all these things.”⁵⁹⁷

As the AIDS industry grew, questions arose as to just how well-compensated “AIDS professionals” ought to be. Former San Francisco AIDS Foundation director Tim Wolfred told me he believed that those who work in AIDS organizations deserve to be paid, even well-paid. “There is work to be done,” he said, “and people doing it deserve to make a decent living.” An executive director responsible for running a multimillion dollar agency must have skills that, as Wolfred pointed out, are in high demand—and compensated with high salaries—in a competitive marketplace. “Despite what it might look like from the outside,” said Wolfred, “I don’t think there is a surplus of people who can manage something of that size. So part of what you’re

⁵⁹⁶. Torie Osborn, interview with author, Washington, DC, 15 February 1995.

⁵⁹⁷. Timothy Sweeney, interview with author, New York City, 2 March 1995.

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doing is paying a competitive salary to keep those skills in place. That's the heart of how our capitalist system works, whether we agree with it or not."⁵⁹⁸

Wolfred's successor at the San Francisco AIDS Foundation, Pat Christen, was clear about why she did the work—and why she deserved a salary commensurate with her skills and experience. Christen was one of the mere 7 percent of all the nation's executive directors of gay and AIDS organizations earning six-figure salaries—she received compensation totaling \$176,742 in 1996.⁵⁹⁹ "I believe strongly that I have considerable skills to lend to this effort and that they should be lent," Christen told me. "I'm not independently wealthy, so I can't do this work and lend these skills unless I get paid for them because I have to pay the rent and I have a daughter to raise. I don't view that as a bad thing that people earn salaries to do good work."⁶⁰⁰

Christen's salary regularly generated considerable protest by members of ACT UP (AIDS Coalition to Unleash Power)/San Francisco, whose leftist ideology didn't keep pace with the growth of the AIDS industry. Beginning in 1998, AIDS activist Michael Petrelis allied himself with antigay Republican members of Congress in criticizing the salaries of AIDS organization directors such as Christen. He failed to acknowledge, however, that even the best paid of them earned considerably less than what the American Society of Association Executives consid-

⁵⁹⁸. Wolfred interview.

⁵⁹⁹. Alan Flippen, "The \$195,000 Question," *The Advocate* (7 July 1998), 41.

⁶⁰⁰. Christen interview.

VICTORY DEFERRED

ered normal for executives of nonprofit groups of comparable size.⁶⁰¹

The influx of a new generation of gay activists who cut their political teeth in ACT UP (AIDS Coalition to Unleash Power) provided the growing AIDS industry with fresh troops to replace the first line of older activists who founded the AIDS organizations, many of whom were burned out by grief and politics or died from AIDS themselves. Although one of the canons of ACT UP's politically pure orthodoxy was that it was a mortal sin to be paid for working on AIDS issues, many of the group's members did in fact move into paying jobs in the AIDS industry.

Once inside the AIDS industry, the perspective of activists often changed as they realized how challenging it is to manage budgets, compromise, and negotiate—to be “professional.” “There are times I really miss those hard moral lines I had as a street activist,” said Jeff Graham, an ACT UP member who served as executive director of Atlanta's AIDS Survival Project from 1994–2007. “Sometimes I get scared that there won't be people keeping me on my toes and reminding me that this is not about careers, and not about jobs, and not about the creation of an industry, but about the elimination of an epidemic.”⁶⁰²

Joe Fera, who, together with Pat Christen, started in the mid-eighties as a volunteer in the AIDS Foundation's speakers bureau, noted that managing the agency's growth to ensure that there would continue to be a San Francisco AIDS Foundation to serve people with HIV required skilled professionals. But

⁶⁰¹. Flippen, “The \$195,000 Question,” 41.

⁶⁰². Jeffrey Graham, telephone interview with author, 13 September 1995.

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like many “old-timers” in AIDS organizations around the country with whom I’ve spoken, Fera rued the loss of what he called the “activist urgency” that charged the foundation in its early years, as people went to work for AIDS organizations because they saw it as “a good career move.” From being a “radical” group—“We used to put out posters of naked men with condoms on their dicks”—Fera said, “We’ve tended to grow into the center. It’s kind of tough to swallow on some level because you want to be out there, and radical, but you find yourself more in the parochial center.” He added wistfully, “That’s an issue that organizations go through as they grow.”⁶⁰³

When GMHC bought and consolidated its operations in one building in 1986, there was a hue and cry among staff and in the gay community as well: How could GMHC spend money that was intended for AIDS services on a building? The controversy over the purchase of the building—which actually proved a wise investment as it increased markedly in value, but which the agency outgrew before too long—is emblematic of some of the reasons for the ambivalence towards the AIDS industry felt by many in the gay community and among long-term staff and volunteers in AIDS organizations.

Derek Hodel, GMHC’s former director of federal affairs, told me in 1995, “There was a visceral revolt on the part of staff, who were upset with the new space.” Although the new building provided the chance to move out of five separate, cramped locations, Hodel said that staff reacted negatively to the new space because it confronted them with the organization’s—and the epidemic’s—permanence in a way they never had anticipated. “All of a sudden this place looked like a bank,” he explained, “instead of the slapdash, haphazard, on-the-fly kind of spaces they’d been using. When folks confronted that, it was

⁶⁰³. Fera interview.

VICTORY DEFERRED

very difficult for them. People didn't want to work there. It changed the quality of their thinking, the way that they felt."⁶⁰⁴

Suzanne Ouellette, a CUNY psychology professor, said that in her studies of GMHC volunteers, she found that most of the volunteers took a "really don't care" attitude towards the agency's bureaucracy as long as it didn't impede their volunteer work. For the staff, though, Ouellette found that the bureaucratization could be alienating, forcing them at times to be dispassionate and "professional" when they might actually have been feeling the "activist urgency" that Joe Fera spoke of. For Ouellette, too, GMHC's physical space provided a metaphor of the mixed blessing that is the AIDS industry. "In the original space," she said, "everyone was on top of everyone else, but you felt a kind of connection. You'd walk in and it was terrible and dirty. But there was a chair lift there. It was rickety, but the chair lift was a clear marker that there were folks coming into and leaving the building who needed help going up the steps. Right away, you knew where you were. Now in the new space, if there weren't the posters, and people didn't take time to decorate their cubicles, you almost could be anywhere."⁶⁰⁵

Like GMHC, AIDS service organizations throughout the country increasingly resembled the "mainstream" agencies whose role they had to fill when gay men were their main clients because mainstream organizations wanted nothing to do with them. Now they could pay their staffs on time, sometimes quite handsomely. Now there were "AIDS professionals" whose entire careers were built from the epidemic. And now a parallel

⁶⁰⁴. Derek Hodel, interview with author, New York City, 27 April 1995.

⁶⁰⁵. Suzanne C. Ouellette, interview with author, New York City, 27 April 1995.

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AIDS fundraising industry had become a profit-making venture for enterprising capitalists, the “activist urgency” too often giving way to packagers, promoters, and profiteers whose “compassion” was available to the AIDS industry—at an often considerable financial and public relations cost. With so many organizations invested in the continuation of AIDS, it seemed that “putting themselves out of business” was the last thing on anyone’s mind.

PART 8

WAR BONDS

*I don't want you to give me your surplus.
I want you to give with personal deprivation.*

ST. TERESA OF CALCUTTA

As always, the efforts of individuals to elicit support, whether volunteer labor or financial contributions, made all the difference in the AIDS epidemic. Gay men hit up their friends for contributions, and gay staffers in the nation's private philanthropic organizations urged their employers to get involved at a time when the federal government still thought AIDS and gay people would just go away if they were ignored long enough. Eventually entertainers and socialites who were either gay themselves or had gay friends overcame their fear of bad publicity by lending their celebrity to the cause of fundraising for AIDS. But the stereotype of gay people as all having white skin, plenty of money, and access to celebrities often hindered their fundraising efforts—especially in the Black community, where big check writers were scarce. Even the AIDS organizations formed by white gay people began to have problems with raising money when questions arose about how, exactly, the money was being spent. Learning about accountability seemed every bit as hard as learning how to raise money in the first place.

TWENTY-EIGHT

More than five thousand people gathered on the beach at the western edge of Fire Island Pines on Sunday, August 20, 1995, for GMHC's thirteenth annual Morning Party. GMHC flags rippled in the ocean breeze as costumed revelers—reminiscent of the famous summer parties in the island's heyday as a gathering place of the gay Beautiful People—danced and sweated with others whose choice of apparel was merely fashion-forward swimwear. The *New York Times* reported the party among the various other charity events it noted in its Sunday "Styles" pages—including another AIDS fundraiser, a party at the Southampton home of theatrical producer Martin Richards to benefit Broadway Cares/Equity Fights AIDS. The Morning Party raised \$350,000 for GMHC.⁶⁰⁶

Times had certainly changed.

When Larry Kramer and his friends canvassed the Pines and Cherry Grove, Fire Island's other mostly gay area, over Labor Day weekend 1981, they netted a mere \$769.55 for the entire weekend. The Pines Pavilion, the hottest dance club in the island's trendiest area, wouldn't let them solicit donations on its premises. And an all-night vigil in front of the Ice Palace, the big dance club in the Grove, by Kramer and his friends Rick Fialla and Paul Popham, brought in a paltry \$126.

In the first four months of raising money for AIDS in New York during that first year of the epidemic, a total of \$11,806.55

⁶⁰⁶. "A Beach Boogie Benefit," *New York Times* (27 August 1995), "Styles" section, 42.

VICTORY DEFERRED

was collected—more than half of it at an August 11, 1981, fundraiser at Kramer's Fifth Avenue apartment. Even then, however, five people had given \$1,000 each and two gave \$500 each. "Which," Kramer noted, "means that the rest of the entire gay community in the city of New York has contributed to this cause the sum of \$5,806.55."⁶⁰⁷

When GMHC cofounder and writer Edmund White's benefit dance committee received the ten thousand printed invitations for the new organization's first major fundraiser—"Showers," an April 8, 1982, disco dance benefit at Paradise Garage—board president Popham was furious that the return address said "Gay Men's Health Crisis." He didn't want the word "gay" to appear on anything sent through the mail lest it force open someone's closet door. "What about my mailman?" asked Popham, mortified to think the mail carrier might know something as private as the fact of Popham's homosexuality. "He's going to know I'm gay." An incredulous Kramer retorted, "What about your doorman? You drag tricks up to your apartment every night. Don't you think your doorman suspects something? Why aren't you worried about him?" Despite fears of being ignored by the many gay New Yorkers for whom being gay meant nothing more than clubbing in the discos on the weekends, "Showers" raised \$52,000 from the apolitical crowd of partygoers.⁶⁰⁸ Kramer told me, "We felt we had the support of the community to do what we were doing, whatever that was."⁶⁰⁹

⁶⁰⁷. Larry Kramer, *Reports from the holocaust: The Making of an AIDS Activist* (New York: St. Martin's Press, 1989), 14–15.

⁶⁰⁸. Randy Shilts, *And the Band Played On* (New York: St. Martin's Press, 1987), 134–135.

⁶⁰⁹. Larry Kramer, interview with author, New York City, 4 March 1995.

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A year after that first benefit, GMHC on April 30, 1983, hosted the largest gay event ever held to that time, and for the first time a charity sold out Madison Square Garden's 17,601 seats in advance. The Ringling Brothers Circus event featured Leonard Bernstein conducting the circus orchestra in the national anthem, as well as a program that contained Mayor Koch's proclamation of "Aid AIDS Week" and page after page of memorial notices of men who had died of the still-mysterious disease.⁶¹⁰ The *New York Native* had helped to promote the event, ensuring its great success, while the *New York Times* ignored it despite the size of the crowd. The circus netted \$250,000, making GMHC one of the wealthiest gay organizations in the country. Still, the circus raised \$100,000 less than the 1995 Morning Party, despite the fact that it drew three and a half times the number of people.

Rodger McFarlane, who became GMHC's executive director shortly after the circus fundraiser, recalled that when GMHC signed the contract with Ringling Brothers to sponsor the event, the group had to come up with an initial \$100,000 payment within three weeks. Where else would they get the money but from their circles of upper-middle-class gay friends? "We went through our phone books of people who could loan us a thousand dollars," recalled McFarlane. A hundred people agreed. "Is that grassroots?" he asked. "It's very green grass." McFarlane attributed the circus's success to the fact that, as he put it, "We had a bunch of white faggots who knew people." Nevertheless, he added, "Considering the disposable income of that group,

⁶¹⁰. Shilts, *And the Band Played On*, 282–83.

VICTORY DEFERRED

we were shocked by the stinginess of it. Everybody thinks it was a groundswell of support, but it wasn't."⁶¹¹

Meanwhile on the other coast, a June 13, 1983, fundraiser for San Francisco's K.S./AIDS Foundation brought out the first entertainment stars to participate in an AIDS benefit. As Randy Shilts noted, most celebrities at that point, "including many who had built their careers on their gay followings, were not inclined to get involved with a disease that was not... fashionable."⁶¹² Actress Shirley MacLaine pulled down the top of her strapless gown to show the audience that she had more than the great legs that host Debbie Reynolds mentioned in introducing her. For her part, Reynolds lifted the back of her own gown to reveal her skimpy black underwear. Television actor Robert "Benson" Guillaume and singer Morgana King joined the others in the symphony hall—which was filled only because the AIDS foundation had given away free tickets.

Cleve Jones recalled Marcus Conant's directness when the doctor first approached him with the idea for the K.S./AIDS Foundation, and the fact that millions of dollars would have to be raised to support the effort. "When Harvey Milk ran for supervisor," said Jones, who worked on Milk's campaigns, "his total campaign budget was \$30,000. I'd never raised that much money." Looking back at the foundation's beginnings, Jones added, "Within a matter of years it became routine for gay community-based organizations to raise and spend millions of

⁶¹¹. Rodger McFarlane, interview with author, New York City, 4 March 1995.

⁶¹². Shilts, *And the Band Played On*, 331.

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dollars every year.”⁶¹³ By the time of my 1995 interview with Jones, the San Francisco AIDS Foundation was operating on an annual budget in excess of \$15 million.

Gay people throughout the country in the early eighties solicited donations from their friends to pay for AIDS services that couldn't be provided by volunteers—and that the federal government most certainly did not pay for. In Atlanta, Jesse Peel threw a fundraiser at his home in July 1984 that raised \$5,000 for the newly formed AID Atlanta. “That was big bucks in 1984!” Peel said with a chuckle.⁶¹⁴

In Miami, Health Crisis Network's (today Care Resource, Inc.) first director, Sally Dodds, remembered a fundraiser in someone's home in Coconut Grove at the end of 1984 that featured singer Barbara Cook and raised about \$8,000. “It was a lot of money,” she said. “We thought we were rich.” One thing that struck Dodds as peculiar, though, was the fact that the gay men at the party wouldn't sign a check to Health Crisis Network, choosing instead to make cash contributions. Of course that way the bank clerks who processed the checks, like Paul Popham's mailman, wouldn't know the men were gay or had given money to a gay organization—or, more to the point, that they were associated in any way with the “gay disease.”⁶¹⁵

⁶¹³. Cleve Jones, interview with author, San Francisco, 2 February 1995.

⁶¹⁴. Jesse Peel, M.D., telephone interview with author, 13 September 1995.

⁶¹⁵. Sally Dodds, telephone interview with author, 13 September 1995.

VICTORY DEFERRED

In February 1985, AIDS Project Los Angeles (APLA) asked actress Elizabeth Taylor to lend her name to its “Commitment to Life” fundraiser to be held in September (as it happened, only weeks before Taylor’s friend Rock Hudson succumbed to AIDS on October 2). Bill Meisenheimer, who was APLA’s executive director at the time, said that Taylor was the first “really big name” star to get involved with raising money for AIDS. Meisenheimer, who counted himself a personal friend of Taylor’s, said, “She had been very angry at people not wanting to get involved, because she had friends who were getting sick and dying, and she couldn’t understand why people wouldn’t get involved. She’ll tell you she was very angry about people sitting on their butts.”⁶¹⁶

On Sunday, July 28, 1985, a huge crowd turned out for an AIDS walkathon that raised \$630,000 for APLA. Los Angeles Mayor Tom Bradley joined movie stars in praising Rock Hudson’s announcement three days earlier that he had AIDS as a main reason for the walk’s success.⁶¹⁷ The AIDS walks had begun a year earlier in Boston, after Mayor Raymond Flynn agreed in 1983 to participate in a cross-state run to raise money for AIDS and suggested in 1984 the event should be a walk through the streets of Boston “to educate everyone,” as Ann Maguire, Flynn’s liaison to the city’s gay community at the time, recalled.⁶¹⁸

⁶¹⁶. Bill Meisenheimer, telephone interview with author, 6 June 1995.

⁶¹⁷. Shilts, *And the Band Played On*, 331.

⁶¹⁸. Ann Maguire, interview with author, Provincetown, Mass., 28 July 1995.

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Other events that became mainstays of AIDS fundraising included dance-a-thons—Boston also pioneered the AIDS dance-a-thon—and, beginning in 1993, various AIDS bike rides. Dan Pallotta, a Los Angeles fundraising consultant, began the California AIDS Ride, from San Francisco to Los Angeles, to raise money for AIDS service providers in the two cities. The rides were extremely successful, at least in terms of raising awareness for AIDS and grossing large amounts of money. The total amount of pledges increased each year from the first ride's \$1.6 million, to more than \$9 million raised in the San Francisco to Los Angeles ride in 1997, the largest AIDS fundraising event to that point.

Most AIDS fundraisers created by gay people didn't have the large corporate sponsors and national promotion of the AIDS rides, because most were done on a small scale at the local level. In Atlanta, for example, Tony Braswell was the executive director of AID Atlanta—by day. By night, though, at least on Sunday nights, Braswell became “May Tag,” a drag queen, camping it up at the Armory, one of the city's gay bars. But not in the Ru Paul mold of pseudo-feminine glamour and curvaceousness. “I'll wear a \$200 ball gown and tennis shoes,” Braswell told me. “We don't shave, don't cover our arms. It's very camp.” Braswell, whose lover of twelve and a half years died of AIDS, performed at the Armory in weekly benefits—he and his costars were called the “Armorettes” (who continue to perform)—that grew out of their efforts in the mid-eighties to raise money for the bar's softball team. “As people began to get sick,” explained Braswell, “we put a bucket out that said ‘This is for people with HIV/AIDS.’” The bucket evolved into the weekly fundraising drag shows to help people meet their medical bills and house payments. The shows further evolved into a more coordinated effort with social service organizations, like AID Atlanta.

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Each November, Atlanta's drag queens compete for the crown in the city's annual AIDS fundraiser, called "Homecoming," by raising money for different AIDS service organizations. Braswell was homecoming queen in 1993 because he raised the most money for the Grady Memorial Hospital infectious disease clinic he directed at the time. He said the event was "very mainstream." After local television anchorwoman Angela Robinson helped Braswell and his friends organize "West Hollywood Squares"—featuring a Hollywood-Squares-like set, participants' names drawn from a hat, and "fabulous prizes"—Braswell said the fundraiser was moved "to a whole new level." He explained, "When she lent her name to it, one of our city council members said 'I want to do it.' The mayor's office called and said they would talk to us. We had several key business people. Now we're 'drag queens to the stars,' as we say."⁶¹⁹

In Atlanta, it took the willingness of a local TV news anchorwoman to get other nongay people involved in raising money for AIDS. Nationally, it took Elizabeth Taylor's announced commitment in 1985 to spur others to follow her lead. Taylor's commitment to AIDS, and the gratitude of gay people to her for it, continued unabated even beyond her death at age seventy-nine on March 23, 2011. At the 1996 International Conference on AIDS, in Vancouver, where reports of successful combination medical treatment changed the course of the epidemic, Taylor received eight standing ovations during her moving speech to the assembled scientists and AIDS activists. As National Minority AIDS Council director Paul Kawata put it, "When

⁶¹⁹. Anthony Braswell, telephone interview with author, 19 September 1995.

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Elizabeth stood up with Rock and said, 'I will give my life to fighting this disease,' it became okay."⁶²⁰

In the years after 1985, celebrities practically tripped over one another to get their names on honorary program committees for AIDS fundraisers and to speak and receive awards for their "compassion" from grateful AIDS organizations. In 1993, when HBO filmed *And the Band Played On*, based on Randy Shilts's 1987 bestseller about the early years of the AIDS epidemic, stars flocked like lemmings to be cast in the made-for-TV movie—but only after Richard Gere agreed to play the small role of a Michael Bennett-like choreographer with AIDS.⁶²¹ Suddenly Steve Martin, Angelica Huston, Alan Alda, Glenn Headly, B. D. Wong, and others found the \$7 million film irresistible. Matthew Modine headed the cast in the role of Don Francis, the CDC scientist who was thwarted at every turn in his efforts to get the federal government to do something to stop the epidemic when it first began. Openly gay actor Sir Ian McKellen played the part of San Francisco's gay political activist Bill Kraus, who succumbed to AIDS in 1986. Lesbian actress and comedian Lily Tomlin played Selma Dritz, the infectious disease specialist in the San Francisco Department of Public Health who, after looking at the extraordinary rates of STDs among gay men in the city just before the epidemic started, warned, "Too much is being transmitted."

It was also in 1993 that Hollywood finally produced a major motion picture that dealt with AIDS, despite the involvement of

⁶²⁰. Paul Akio Kawata, interview with author, Washington, DC, 24 March 1995.

⁶²¹. Bernard Weinraub, "Stars Flock to Be in HBO Film About the Early Years of AIDS," *New York Times* (11 January 1993), C11.

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individual actors and the movie industry's professed concern in its October 1991 formation of Hollywood Supports, an organization intended to assist those in the film business affected by AIDS. Tom Hanks starred as AIDS-stricken gay lawyer Andrew Beckett in *Philadelphia*, one of the most successful dramatic films of 1993, earning \$125 million at the box office worldwide before being released on video.⁶²² When he was asked whether it was a difficult career decision to portray a gay man with AIDS, Hanks said, "I'm greatly pleased and very, very honored to have been a part of the first mainstream, big budget, American motion picture to deal with the subject matter."⁶²³ I wept along with Hanks—and my ex-lover Bill, who entered the hospital two days later for what proved to be his own last round with AIDS—as the actor recalled his gay theater-teacher heroes in a tearful acceptance speech for the "Best Actor" Oscar during the Academy Awards presentation on March 21, 1994.

One of the worst kept celebrity "secrets" ended in 1994 when singer Elton John finally admitted that he is gay. To his credit, John at that point was already using his popularity to raise substantial amounts of money for AIDS causes, channeled through the Elton John AIDS Foundation he formed in 1992. That year he contributed all the proceeds from his singles sales in America of "The Last Song," a moving song about a young man with AIDS making peace with his father before the son dies. Once he finally committed himself, John raised millions for AIDS. But, he noted, "I didn't really get involved until I spent some time with Ryan [White's] family and met Ryan and

⁶²². Clifford Rothman, "'Philadelphia': Oscar Gives Way to Elegy," *New York Times* (1 January 1995), H9.

⁶²³. "Q&A" Tom Hanks: There Are 'A Zillion More Stories' Hollywood Should Be Telling," *Washington Blade* (28 July 1995), 43.

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saw the injustices that his family had to endure because of AIDS.”⁶²⁴

The biggest celebrity athlete AIDS story after Magic Johnson’s 1991 announcement that he was HIV-positive, and Arthur Ashe’s April 8, 1992, press conference to confirm rumors that he indeed had AIDS, was the 1995 revelation by four-time Olympic gold-medal diving champion Greg Louganis that not only was he gay but that he was HIV-positive as well, and had in fact already suffered several AIDS-related bouts of illness. Louganis immediately became the highest-profile gay men ever to go public at one time about both his homosexuality and his HIV infection. In his autobiography *Breaking the Surface*—which premiered at number one on the *New York Times* best-seller list on March 19, 1995—Louganis said he decided to write the book after a health scare made him realize he might not have long to live. “I don’t want to wind up like Rock Hudson or Liberace,” he (and coauthor Eric Marcus) wrote. “Rock Hudson only came forward with the truth at the very end of his life, long after he was in a position to tell the public himself. Liberace died hoping to take his secret with him. I want to be able to do this with dignity, to stand up with a sense of pride in who I am, to say, ‘This is who I am and this is what I have and this is what I’ve done.’”⁶²⁵

By the end of 1995—a decade after Rock Hudson went public about having AIDS, and his friend Elizabeth Taylor made the epidemic “okay”—many celebrities and other wealthy and socially prominent people had jumped on the AIDS bandwagon.

⁶²⁴. Ingrid Sischy, “Elton John: 150% Involved,” *Interview* (April 1995), 74.

⁶²⁵. Greg Louganis, with Eric Marcus, *Breaking the Surface* (New York: Random House, 1995), 272.

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Singer Deborah Harry (Blondie), whose song “The Tide Is High” set the whimsical but determined tone of the 1990 AIDS film *Longtime Companion*, played a benefit concert on September 3 at the Town Hall in Provincetown, Massachusetts, to assist the Provincetown AIDS Support Group. “It fit my schedule, I thought it would be fun, and it’s P-town,” said Harry, adding, “And of course it’s AIDS.”⁶²⁶ That year, pop singer Cyndi Lauper and jazz singer Dianne Reeves performed at the closing ceremonies of Whitman-Walker Clinic’s ninth annual AIDS walk in the nation’s capital, led by Tipper Gore.⁶²⁷ And comedian and talk-show hostess Rosie Perez walked a ten-kilometer “act of penance” in the AIDS Walk Colorado to raise money for AIDS services and to assuage her conscience after not visiting a friend in the hospital with AIDS until the day after the man had died.⁶²⁸

Blaine Trump got involved with God’s Love We Deliver, New York City’s meals program for people with AIDS, after losing friends and “because she’s a caring soul,” as executive director Kathy Spahn put it.⁶²⁹ Others of her wealth and social standing also got involved because they knew someone affected by AIDS, or because they knew someone who knew someone with

⁶²⁶. Chronicle: “Deborah Harry in a Summer’s-End AIDS Event,” *New York Times* (22 August 1995), B2.

⁶²⁷. “Cyndi Lauper to Perform at AIDSWALK Concert; Diane Reeves to Round Out Closing Ceremonies,” *Washington Blade* (15 September 1995), 2.

⁶²⁸. Chronicle: “For Rosie Perez, a 10-Kilometer Act of Penance in Memory of a Friend,” *New York Times* (11 September 1995), B-12.

⁶²⁹. Kathy Spahn, telephone conversation with author, 17 August 1998.

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AIDS. Either way, there was a personal connection to the disease—typically far fewer than six degrees of separation. They volunteered time, contributed money, and urged their friends to do the same because the epidemic had become real for them.

To the dismay of AIDS fundraisers, though, the unwillingness of many closeted, wealthy gay men to be open and honest prevented their wealthy heterosexual friends who may have been willing to contribute from knowing how they might help or how much they might be able to donate. In Washington, D.C., I reported on the segregation between gay and heterosexual people that for years was a major handicap for AIDS fundraising efforts in the city. The lack of connections by AIDS service providers to Washington's charity-ball set hindered the providers' ability to procure for their own work some of the money those wealthy people contribute to other charities.

But it was more than that. In a city where A-lists are predominantly political (with a handful of real estate developers and media celebrities thrown in), the arts crowd—the artists, fashion designers, and entertainers who were hit by AIDS early and hard because of the large number of gay men among them—doesn't have the same social cachet with the fashionable party throwers that it has in cities like New York and Los Angeles. The lack of social cross-pollination meant that, for many years, prominent Washingtonians often remained isolated from AIDS, the epidemic being nothing more to them than the background noise among "the masses."

Many of the gay men who moved among Washington's wealthy and high-powered—even men whose own lovers were known to have it—were loath to speak about AIDS with their heterosexual colleagues for fear of being associated with the stigmatized disease. Riley Temple, a Whitman-Walker Clinic board member at the time, told me in 1990, "There are [gay]

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people who would ordinarily move in those circles who for many reasons feel it's risky even to bring the [AIDS] topic up. They're afraid their business or social colleagues would associate them with a disease that is usually associated with the kinds of people who would not frequent those events." Gay men whose primary need was to be accepted by heterosexuals—to be insiders in a city populated by people who crave insider status—could not bring themselves to associate in any way with a disease that, above all else, has been seen, in this country, as a disease of "outsiders."

Jennifer Phillips, a trustee of her family's modern-art museum, the Phillips Collection, described a "voluntary segregation" between Washington's gay and heterosexual communities. "I don't think there's a tremendous amount of interaction," she told me in 1990. "The gay community is not very 'out' in Washington, as it is in Key West, for example, where I have spent the last several winters and where there is integration of the homosexual and heterosexual communities." It was her gay friends in other places who spurred Phillips to get involved with AIDS causes in Washington. Even when she and her husband, Laughlin, signed up for an Art Against AIDS committee, it was because professional New York fundraisers asked them. Local AIDS fundraisers—from Whitman-Walker Clinic, for example—hadn't approached them or others like them who had money and the desire to give it. "I've been amazed," said Phillips, "that the AIDS community is not doing as much reaching out to people like me." Even the clinic's Riley Temple admitted, "I don't think it's that [society] people are not willing to get involved—we just haven't asked them."⁶³⁰

⁶³⁰. John-Manuel Andriote, "Society Gets AIDS," *Washington Dossier* (December 1990), 32–35.

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Throughout 1990, Michelangelo Signorile, in his weekly *Out-Week* “Gossip Watch” column, hammered David Geffen, one of the wealthiest men in Hollywood and at the time still a closeted homosexual. “I don’t care how much blood money you’ve given to fight AIDS,” wrote Signorile in a typically histrionic column. “You slit our throats with one hand and help deaden the pain with the other.” In September of that year, Geffen’s name appeared on the benefit committee of APLA’s annual “Commitment to Life” fundraising event. After seeing the event’s guest list, a Los Angeles group, Artists Confronting AIDS, sent a protest letter to APLA saying, “Commitment to Life?! Honey, next year call it what it really is: Commitment to the Closet.” After sticking a tentative toe out of the closet in a February 1991 *Vanity Fair* interview—he claimed he was “bisexual”—Geffen finally came out fully as a gay man at the end of 1992, when he received an award from APLA for his contributions.⁶³¹ In March of that year, Geffen had given \$1 million to APLA for new office space.⁶³² He has since given millions more to other AIDS organizations, including GMHC and AIDS Action Council.

The undeniably important contributions of time, money, and lucrative connections that people like David Geffen, Elizabeth Taylor, Blaine Trump, and many others made to support AIDS services, raise one troubling but important question: Where were these people before AIDS? Why weren’t they there to assist gay people as they struggled to achieve equality and to lessen the hatred and violence towards them?

⁶³¹. Michelangelo Signorile, *Queer in America: Sex, the Media, and the Closets of Power* (New York: Anchor Books/Doubleday, 1993), 302–309.

⁶³². David J. Fox, “Geffen Gives \$1 Million to AIDS Group for New Office Space,” *Los Angeles Times* (3 March 1992), B1.

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Some of them, like Geffen and Elton John, were hiding their homosexuality in closets lined with vast amounts of money. But the others? Elizabeth Taylor? She was widely known to have a number of gay friends, including Rock Hudson, yet it wasn't until they were diagnosed with a fatal illness that she saw the need to speak out on their behalf. As Tim Wolfred, the former director of the San Francisco AIDS Foundation, put it, "Who would speak out for us before AIDS? Who would publicly defend us? America wasn't ready until we were dying, when we had this epidemic. Before then, all the public images of us were twisted, perverted, and nobody spoke up against that—not even gay people themselves."⁶³³

Indeed, heterosexuals and wealthy but closeted gay men weren't the only ones to avoid gay community organizations and fail to speak out on behalf of gay people before AIDS. Most of the gay and lesbian rank and file also weren't involved in, or did not give money to, gay political and social service organizations until the AIDS epidemic showed them their connections to one another and the political implications of their personal lives. Also like too many heterosexuals, many gay people didn't contribute or get involved with AIDS until someone told them it was acceptable to do so. As Urvashi Vaid points out, "As AIDS activism and fundraising developed a social cachet—through the involvement of straight celebrities and wealthy individuals—more gay people felt comfortable getting involved."⁶³⁴

⁶³³. Timothy Wolfred, telephone interview with author, 30 September 1995.

⁶³⁴. Urvashi Vaid, *Virtual Equality: The Mainstreaming of Gay & Lesbian Liberation* (New York: Anchor Books/Doubleday, 1995), 77.

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By staying in the “closet” about their sexual orientation or concern about AIDS, many gay people hoped to avoid being labeled and stigmatized by disapproving heterosexuals. But this attitude also prevented heterosexuals from seeing gay people as real human beings. As efforts to raise money for AIDS showed time after time, whether for an AIDS walk or a corporate contribution, the willingness of gay people to be open and honest about their lives, fears, and pain, has enormous power to heal them—and to win allies who share their humanity and concern. As with everything else gay people accomplished in the AIDS epidemic, being honest and having integrity took courage and a refusal to buy into the shame that many heterosexuals want to impose on gay people and on AIDS. Which goes to show that love, concern, and the drive for survival eventually win out over fear and even the need for approval.

TWENTY-NINE

Before AIDS, Atlanta psychologist Don Smith said his city's gay community "wasn't enormously visible except on the bar circuit." In the early eighties, though, Smith wasn't part of the bar scene, and was just coming out as a gay man. "Once I saw the AIDS epidemic was going on," he remembered, "it was like this was far too important for me to worry about what the public thought of my sexual orientation." In March 1983, Smith got involved with AID Atlanta as a volunteer support-group leader. The organization had no paid staff, and in fact, said Smith, "To call it an organization at that point was an overstatement; it was more like a disorganization." Raising money for services was tough going, especially because the bar owners thought that talking about AIDS was "bad for business." That changed, though. Said Smith, "When the bartenders and owners started to die, fundraising became very successful in bars." Suddenly, the bars that were for many gay people the center of their social lives said it was okay to talk about AIDS, and this even made AIDS fundraising fashionable.⁶³⁵

The history of private-sector AIDS fundraising is a collection of stories like Smith's. Just as Elizabeth Taylor made AIDS a legitimate cause for celebrities—both heterosexual and gay—by her own example, others with money to give or fundraising skills to offer came forward only when someone they respected said it was not only necessary but that it was okay to do so. That's how it happened not only in the gay bars and among celebrities and the wealthy, but also in the nation's philanthropic

⁶³⁵. Donald Smith, telephone interview with author, 16 September 1995.

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foundations and charitable organizations. Typically a gay man who either had AIDS himself or knew someone who did, or a sympathetic heterosexual, most often a woman, would call attention to the epidemic and point out how his or her employer could provide funding assistance to a struggling community AIDS organization.

In 1986, the Ford Foundation asked Michael Seltzer—a gay man long involved with philanthropy and, at the time, cochair of Lambda Legal Defense and Education Fund—to survey the landscape of foundation giving for AIDS and advise them on how they might respond. Seltzer published his findings in a 1987 report titled *Meeting the Challenge: Foundation Responses to Acquired Immune Deficiency Syndrome*. He also spearheaded the 1987 launch of a Council on Foundations affinity group, called Funders Concerned About AIDS. The group was formed to educate those in the foundation world about AIDS, and the role that private philanthropic funding could play in responding to the epidemic. Seltzer, who shortly after our 1995 interview left his position as the founding executive director of Funders Concerned to join the staff of the Ford Foundation, said, “When AIDS dropped like a bomb into the foundation world, people didn’t know about it unless they knew somebody who was gay.”

At Funders Concerned, Seltzer’s job was to educate foundations about the ways in which AIDS was relevant to their areas of concern. For a program on AIDS and Black women’s health, for example, Seltzer brought in the executive editor of *Essence* magazine to speak about why funders should be interested in Black women’s health. For foundations interested in the arts, Funders Concerned showed them why AIDS is an arts issue. Rather than encouraging foundations to create AIDS programs per se, Seltzer said, “Our goal is to help them under-

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stand the links between their interests and the opportunities to respond to AIDS.”⁶³⁶

The lessons that Seltzer and Funders Concerned attempted to impart to the nation’s private foundations were long overdue by the time serious money finally began to be channeled to AIDS prevention and services. Although the AIDS epidemic was designated as such in 1981, it wasn’t until 1983 that four foundations made five small grants. Despite the fact that AIDS was being called the greatest public health crisis of the century, it was only in 1987 that two dozen of the more than thirty-two hundred foundations nationwide actually made grants for AIDS.

Like the federal government, most foundations took a wait-and-see attitude toward AIDS in the early years. Briefly, it went something like this: “Let’s wait until we know whether predictions come true about AIDS ‘breaking-out’ into the ‘general population’”—that is, into the white heterosexual middle class. “In the meantime let’s see just how long gay people can foot the entire bill for ‘their’ epidemic.” As for many individual Americans, the 1985 death of Rock Hudson was a turning point in the awareness of AIDS by foundations, according to Seltzer’s 1987 report. “The heightened visibility of AIDS in the country at large also had a notable effect on foundation funding efforts,” it said.

A year after the Ford Foundation report, another study of philanthropic AIDS funding, by the Foundation Center, noted that by August 1988 some 157 foundations had awarded 593 grants for HIV/AIDS programs, totaling \$51,599,545. Thirty-one million of those dollars had been allocated in the 1987 funding year—not coincidentally the first funding year after Rock Hudson’s October 1985 death. Still only 3 percent of the nation’s

⁶³⁶. Michael Seltzer, interview with author, New York City, 4 March 1995.

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foundations that make awards larger than \$100,000—to wit, the wealthy ones—had given money to AIDS causes at that point. At the time of the Foundation Center report, there were seventy-three thousand AIDS cases in the United States.⁶³⁷

Of the private foundations that had given money for AIDS by 1988, the Princeton, New Jersey-based Robert Wood Johnson Foundation (RWJ) was far and away the largest single funder, having given nearly \$27 million—more than half of all the private foundation funding for AIDS to that point. RWJ's single largest AIDS grant was in 1988 for \$4 million to WGBH, the public television station in Boston, to produce *The AIDS Quarterly*, an educational series hosted by Peter Jennings. But to be able to contribute money for AIDS, RWJ, the nation's largest health care philanthropy, had to find a way around its policy of not making grants for particular diseases.

Paul Jellinek, then RWJ's vice president for programs, explained how the foundation came to see AIDS as relevant to its interests. "We actually had a very interesting internal debate about whether or not to get involved with AIDS," said Jellinek. "In part it was because we were not focused on specific diseases, but also it was not clear what our role would be if we got into this. At that point, fewer than 20 percent survived more than two years after diagnosis. From a health care standpoint, there was little to do other than palliative care. Our major emphasis had always been health care." Jellinek said that RWJ didn't see basic research as a needy area because it was (presumably) being handled by the National Institutes of Health. Epidemiology was the bailiwick of the Centers for Disease Con-

⁶³⁷. John Clinton, ed., *AIDS Funding: A Guide to Giving by Foundations and Charitable Organizations* (Washington, DC: The Foundation Center, 1988).

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trol. And public education was supposed to be the province of the surgeon general.

“So it was not clear what role, if any, we might play,” Jellinek continued. When Dr. Philip Lee, from the University of California–San Francisco, told RWJ about the “San Francisco model” of coordinated AIDS care, it was a revelation. Said Jellinek, “We recognized that there are service needs here, a real need for home and community-based services. If those services were not available, people with AIDS might wind up being hospitalized inappropriately, or sent home without adequate support services.”⁶³⁸

RWJ responded by establishing its \$17.1 million AIDS Health Services Program, the pilot projects intended to replicate the San Francisco model of coordinated AIDS services. In March 1988, the foundation solicited proposals from community-based organizations for AIDS prevention and service projects focusing on those at highest risk. RWJ didn’t specify the level of funding it would make available for the projects—and was overwhelmed by more than one thousand proposals requesting a total of \$537 million. The foundation ultimately selected fifty-four projects, totaling \$16.7 million.⁶³⁹

How did RWJ’s example affect other foundations? The federal government? Jellinek said, “We were somewhat disappointed that the size of the response wasn’t greater. There was a broad response, with a lot of foundations [giving money], but

⁶³⁸. Paul Jellinek, telephone interview with author, 10 February 1995.

⁶³⁹. Vivian E. Fransen, ed., *Proceedings: AIDS Prevention and Services Workshop, February 15–16, 1990* (Princeton: Robert Wood Johnson Foundation, 1990).

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not always at the level we had hoped given the severity of the situation.” As independent entities, Jellinek explained, foundations have an advantage over, say, the US Congress, in that they can pick an issue or organization they’re interested in funding and move on it relatively quickly. In an odd twist, though, RWJ found itself not only pointing the way for a hesitant federal government, but also trying to fill a gap that should have been filled by the Feds.

Though he didn’t speculate as to why the federal government took so long to make an appropriately substantial financial commitment to AIDS, Jellinek tactfully said, “We were pleased that in fact some of these programs made it easier for the federal government to move forward. The HRSA [AIDS services demonstration] program was modeled after RWJ, which in turn was modeled after San Francisco, which subsequently laid the groundwork for [the] Ryan White [CARE] Act. The AIDS Prevention and Services projects made it easier for CDC to open their funding directly to community organizations.”⁶⁴⁰ For decades privately funded groups were looking at the kind of long-term care that infectious or chronic diseases would require. But with AIDS, “a foundation program served as a surrogate for, rather than as an example to, the federal government,” as Daniel M. Fox puts it in *AIDS: The Burdens of History*.⁶⁴¹

The Ford Foundation responded to Seltzer’s 1987 report by launching the National–Community AIDS Partnership (NCAP) the following year, with an initial \$2 million, to be housed at the

⁶⁴⁰. Jellinek interview.

⁶⁴¹. Daniel M. Fox, “AIDS and the American Health Polity: The History and Prospects of a Crisis of Authority.” In Elizabeth Fee and Daniel M. Fox, eds., *AIDS: The Burdens of History* (Berkeley: University of California Press, 1988), 333.

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National AIDS Network. Seltzer said, “I suggested we needed to create an entity that would be respected by foundations and corporations at the national level. That was the genesis of the National AIDS Fund [as NCAP is known today].” The National AIDS Network folded two years after the philanthropy was established, but Paula Van Ness remained the Fund’s president. She could have been speaking for AIDS-related causes in general when she said of her own experience, “What could have been a short-term job has turned into a long-term job.”⁶⁴²

The National AIDS Fund took the concept of community-wide planning—RWJ used this in its local planning consortia, and the Ryan White CARE Act continues to use it in distributing the federal government’s billions for AIDS services—to make funding awards on a matching basis. Money from national foundations channeled through the Fund was matched with money generated by the Fund’s thirty-two “community partners” around the country. Van Ness explained that if, for example, the Fund had \$75,000 to give, a grant was awarded to an interested community only after it formed a local advisory committee, conducted a community needs assessment, and used the funds to leverage an additional \$75,000 from local charitable funders. In its first decade the Fund raised more than \$70 million for organizations providing AIDS prevention and care, and its community partners gave a record \$10 million in 1997 alone.⁶⁴³ Starting in 1993, the Fund administered money raised by Elton John through his Elton John AIDS Foundation. As Van

⁶⁴². Paula Van Ness, interview with author, Washington, D.C., 25 April 1995.

⁶⁴³. National AIDS Fund, “Why You Should Support the National AIDS Fund’s 10th Anniversary Campaign” fact sheet, 1998.

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Ness put it, “Elton John is the money machine; we’re the distribution department.”⁶⁴⁴

The first national philanthropic foundation focusing exclusively on AIDS was formed by people who were seeing young gay colleagues get sick and die, and wanted to do something to help. The design and fashion industries were hit hard by AIDS because of the disproportionately large number of gay men who work in them. The growing toll led a group of industry people to join textile designer Patricia Green on April 25, 1984, to form the Design and Interior Furnishings Foundation for AIDS. At its tenth anniversary, in 1994, the foundation changed its name to the Design Industries Foundation Fighting AIDS, though it continues to be known most commonly as DIFFA. Green recalled the reason others responded so readily to the letter she had sent around to colleagues in the industry. “There was a sense of desperation among us,” she said, “that we had to do something, right now, that nobody was listening while all around us, our friends and colleagues were disappearing and dying.”⁶⁴⁵

Like many people involved in fighting and raising money for AIDS, DIFFA’s organizers were struck by the firsthand experience of someone actually living with AIDS. At an early meeting of the group at the Manhattan offices of the American Society of Interior Designers, Richard Medrano, a young Mexican-American designer, stood and addressed the group forthrightly about his illness. Mathilde Krim, who in 1983 had formed the AIDS Medical Foundation in New York, was there, as was Rodger McFarlane, then director of GMHC. For many it was the first

⁶⁴⁴. Van Ness interview.

⁶⁴⁵. Drawn from a DIFFA advertising supplement to the *New York Times Magazine* (26 June 1994).

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time they'd heard someone with AIDS talk without shame about what it was like to live with the highly stigmatized disease.⁶⁴⁶

In its own first decade, DIFFA had raised and distributed nearly \$19 million to more than six hundred community-based organizations across the country to support their efforts to provide direct care, education, and prevention. Twenty affiliated chapters and organizing committees throughout the U.S. raised funds and awareness largely through special events that drew from their local design industries. As *Art & Understanding* put it, "By capitalizing on the talents and products of top artists, designers, corporate leaders, and celebrities, DIFFA produces events that seem almost magical when compared to many others."⁶⁴⁷ Almost equally magical was the fact that DIFFA seemed to be an efficiently operated charity, at least until a substantial loss on a series of fundraising parties in 1994 forced questions about the group's overhead costs—because it had found ways to raise money that relied heavily on volunteers and donated goods and services, as did AIDS service organizations in the early years.

To think that DIFFA began because Pat Green had been affected by the death of a friend is to be reminded of the power of one: one life lost, and one person's commitment to make a difference. As Green put it, "People get involved with organizations like DIFFA not because of the huge amounts of numbers of people that have died, because you can hear that ten thousand people died last year and still not have it seem real. It's not until you have it happen to you—until you lose one person,

⁶⁴⁶. Ibid.

⁶⁴⁷. Nick Steele, "Design for Dignity: DIFFA's Innovative Decade in the War Against AIDS," *Art & Understanding* (January/February 1995), 25.

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know one person who has died of AIDS—that it really changes everything.”⁶⁴⁸

Not one death, not even tens of thousands of deaths, could move the Reagan administration to assert authority in the nation’s response to the growing AIDS epidemic, and it was left to Congress to appropriate more funds than the administration requested for research into the mysterious disease. A 1985 report by the congressional Office of Technology Assessment noted that “increases in funding specifically for AIDS have come at the initiative of Congress, not the administration.”⁶⁴⁹ At least partly because of the administration’s reluctance to fund AIDS research during the first few years of the epidemic, Daniel Fox noted, “voluntary contributions and state appropriations for laboratory and clinical investigation have been more important than in other recent epidemics.”⁶⁵⁰

This was where the American Foundation for AIDS Research (AmFAR) came in. In 1983, Mathilde Krim, a PhD research scientist whose now deceased multimillionaire husband Arthur was chairman of Orion Pictures, was alarmed by news from her colleague Joseph Sonnabend about the strange symptoms that were afflicting his gay patients in Greenwich Village. With more than \$100,000 of her own family funds, Krim formed the AIDS Medical Foundation in New York. In 1985, the foundation merged with a similar Los Angeles-based organization called the National AIDS Research Foundation—which had

⁶⁴⁸. Ibid.

⁶⁴⁹. US Congress, Office of Technology Assessment, *Review of the Public Health Service Response to AIDS* (Washington, DC: OTA, 1985).

⁶⁵⁰. Fee and Fox, *AIDS*, 330.

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been started by Michael Gottlieb, Rock Hudson's personal physician, among others—and AmFAR was born. Krim's scientific credentials and, even more importantly, social cachet among the rich and famous, brought substantial attention to AIDS and contributions to AmFAR. A quarter-million dollars from the estate of Rock Hudson helped launch the foundation, and the role of Elizabeth Taylor as its national spokeswoman brought the foundation immediate prominence, glamour, and “mainstream” acceptability.

Bill Meisenheimer, who left his job as director of AIDS Project Los Angeles in October 1985 to become AmFAR's first executive director, explained that the foundation's mission “was to promote development of research through seed grants so people could go get real grants.” AmFAR had a significant advantage over other AIDS groups in that it was not seen as a “gay” organization, which was intentional. Said Meisenheimer, “A more mainstream organization could perhaps appeal to people who wouldn't relate to a grassroots—gay—organization.”⁶⁵¹

To further enhance both its credibility and visibility, AmFAR brought on Mervyn Silverman, the former health chief from San Francisco who was later hired by the Robert Wood Johnson Foundation to direct its AIDS Health Services Program, as president of its board. Silverman, who was still AmFAR's president in the mid-nineties, told me, “By being private, rather than government funded AmFAR could be creative, flexible, and fast. Few of those words apply to government. The government hadn't demonstrated the capacity to make a difference. AmFAR could be a catalyst for young researchers to try ideas. In the

⁶⁵¹. Meisenheimer interview.

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early years, every dollar we put into research germinated twenty-seven times that amount.”⁶⁵²

It was almost six years to the day after Michael Gottlieb’s first published report of mysterious cases of *pneumocystis* pneumonia among five gay men in Los Angeles that President Reagan finally spoke publicly about the AIDS epidemic. It was not surprising that he chose to do so at a May 31, 1987, AmFAR benefit dinner in Washington, because the presence of Elizabeth Taylor and other heterosexual actors and celebrities ensured that Reagan would feel at home. Of course the death of the president’s friend and White House guest Rock Hudson two years earlier hadn’t inspired him to speak about AIDS then, even as America shuddered with fear of the disease.

The \$250-a-head AmFAR crowd booed Reagan’s call for “routine” HIV antibody testing of certain groups of people in the tent that had been erected for his sideshow before the actual dinner. Meanwhile, outside the tent I marched and shouted with the hundreds of others who had come to protest Reagan’s years of negligence on AIDS and draconian, politically motivated measures against unpopular groups. Stephen Beck, then director of the National Association of People with AIDS, said, “People with money, let’s call them the elite, can go to dinner and they can feel comfortable thinking about AIDS as an issue. What we’re trying to demonstrate is that when we’re talking about AIDS, we’re talking about people.” The people I was talking about as I marched in the protest that night were my friend Allen in New York, bedridden and blind from cytomegalovirus, and my then twenty-eight-year-old friend Gregg in Chicago,

⁶⁵². Mervyn P. Silverman, MD, telephone interview with author, 15 February 1995.

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who had just learned he was HIV-positive and referred to himself as “damaged goods.”⁶⁵³

The “power of one” inspired people and organizations to take action and contribute money. The power of many, and of their money, was amazing to witness. Unfortunately, the good will and generous donations couldn’t keep the viral enemy at bay. What’s more, the fallout of its assaults included the breakdown of good will between concerned people. Even in this war, “officers” too often pursued their own agendas, dividing the ranks and hindering the cause to make a point. Even in this war, American racial politics too often hindered the battle against AIDS.

⁶⁵³. John-Manuel Andriote, “AIDSweek: May 31–June 5,” *Washington City Paper* (12 June 1987).

THIRTY

One of the most insidious stereotypes about gay people is that they are all affluent and white. Of course no one can deny that the first people in this country to be afflicted by AIDS were the relatively affluent white gay men living in the gay ghettos of the large coastal cities in the seventies and early eighties. At the same time, though, no one can deny that those men also were the first to rally in response to AIDS by caring for the afflicted, raising money to provide services, and educating others about the disease. Unfortunately the public image of gay men has tended to focus less on their compassion and generosity in the epidemic than on the fiscal wherewithal of a small but highly visible segment of the community.

This image has worked against gay people at the highest levels of government by giving the impression—though of course people see what they choose to see, no matter how selectively incomplete the picture—that the gay community could take care of its own, without assistance from the federal government, like other Americans. In fact, the Presidential Commission on the Human Immunodeficiency Virus Epidemic, created by President Reagan in 1987, observed that part of the reason for the government's failure to fund AIDS programs at a level commensurate with its own declarations of AIDS as the nation's top health priority was the belief that AIDS was limited to a well-organized, affluent segment of the population.⁶⁵⁴ Even conservative Supreme Court Justice Antonin Scalia implied that

⁶⁵⁴. Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic (Washington, DC: Government Printing Office, 24 June 1988), 117.

VICTORY DEFERRED

gay people are all affluent—they “have high disposable income,” he wrote—in his dissent from the court’s 1996 decision striking down Colorado’s antigay Amendment 2.⁶⁵⁵

To dispel the myth of universal gay wealth and skin tone, all you need to do is talk with people who provide AIDS services and health care in cities throughout the country. At AIDS Action Committee in Boston, for example, then-executive director Larry Kessler told me as early as 1995, “We seldom get the yuppie gay man. It’s more of a lower-class issue, poor white or Black. It’s more like the crowd you’d see in a soup kitchen. Someone with lots of insurance, a housemate, lover, or family, isn’t likely to be at our Monday night dinner as they once were.”⁶⁵⁶ In Chicago at the time, the Howard Brown Memorial Clinic’s clientele were mostly gay. But then-director Eileen Durkin said, “We see a lot of people come in here for primary care who are service workers—waiters, for example—who are amongst the working poor; they don’t have health insurance.”⁶⁵⁷ And in Baltimore, Dr. Joe O’Neill said, “Amongst the maybe 20 to 30 percent of gay patients I have, most of them have been medically indigent, or have drug use problems—problems that aren’t significantly different from anybody else living in a housing project or inadequate situations in the inner-city of Baltimore.”⁶⁵⁸

The misguided perception of all gay people as wealthy and white has had major implications for the ways in which AIDS

⁶⁵⁵. Steve Friess, “Are Gays Really Rich?” *The Advocate* (28 April 1998), 37.

⁶⁵⁶. Larry Kessler, interview with author, Boston, 24 July 1995.

⁶⁵⁷. Eileen Durkin, interview with author, Chicago, 1 June 1995.

⁶⁵⁸. Joseph P. O’Neill, MD, interview with author, Washington, DC, 29 August 1995.

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service organizations receive funding, whether from the federal government or private sources. Frank Pieri, chairman of Howard Brown's board at the time of our 1995 interview, said the city of Chicago's attitude toward gay organizations such as the health center was that "they have more money and more resources, and they should support themselves—they shouldn't rely on city dollars." Increasingly, however, even the organizations that were founded by white gay men in the early years of the epidemic served nonwhite, even nongay clients. But that didn't necessarily translate into more funding to provide those services. Echoing remarks I heard across the country, Pieri said, "For the most part, they are funding minority organizations, or organizations that are willing to go into minority neighborhoods. And they're not funding what they perceive as gay white male institutions."⁶⁵⁹

Tim Sweeney, who for four years directed GMHC, the nation's oldest AIDS service organization, said, "People have looked at the gay community and said 'You have access to private dollars.' But if and when those private dollars aren't there for the gay community, then what happens? Because they're not always there. And just because they're there in New York or San Francisco or Los Angeles doesn't mean they're going to be there in Omaha." Sweeney noted that the vast majority of gay Americans don't have access to organizations like GMHC that can pull in rich movie stars and classical musicians to do fundraisers. He added, "I get really uncomfortable with those broad generalizations that are based on a handful of organizations."⁶⁶⁰

⁶⁵⁹. Frank Pieri, M.D., interview with author, Chicago, 3 June 1995.

⁶⁶⁰. Timothy Sweeney, interview with author, New York City, 2 March 1995.

VICTORY DEFERRED

Urvashi Vaid attributed the image of gay homogeneity and disposable income to surveys that have been conducted of the readers of gay and lesbian magazines—a typically more educated and affluent group of people—and the visibility of upper-middle-class gay people. Lorri L. Jean, executive director of the Los Angeles Gay and Lesbian Center, the nation's largest and wealthiest gay social services organization, concurred with Vaid's assessment. "It worries me," she said, "when a lot of us claim that the gay community is wealthier, has a higher per-capita income, all those things, because I think they're only surveying a certain slice of our community. In fact many in our community are barely above the poverty level or below it, just workaday blue-collar folks."⁶⁶¹

Again, to dispel the myth of universal gay wealth and skin tone, just talk with Archbishop Carl Bean, the Black gay minister who founded the Minority AIDS Project. Based in the impoverished South Central area of Los Angeles, MAP has been among the nation's largest AIDS service providers for African-Americans. Yet the agency has struggled for its life since its 1985 birth. A lack of interest by wealthy white gay people, the furtiveness of many Black gay and bisexual men, a shortage of wealthy, openly gay Blacks willing to give money, and an ever-growing caseload have kept the Minority AIDS Project close to the edge. "We're still struggling," Bean told me in 1995. "We struggle to pay payroll. We struggle to keep the doors open."

⁶⁶¹. Lorri L. Jean, telephone interview with author, 26 October 1995.

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We struggle to keep the pantry full. Most of the time it isn't full, and payroll is late, and we borrow from Peter to pay Paul."⁶⁶²

In many cities, including Los Angeles, the AIDS service organizations established by white gay men expanded as the epidemic expanded, providing services to any and all who needed them. At GMHC, the progenitor of all AIDS organizations, the drive to "be all things to all people" led to what Linda Campbell, then director of the Minority Task Force on AIDS—New York's largest and oldest AIDS service organization founded in 1985 by and for people of color, known today as FACES, NY—described as a kind of colonialism. Although nearly half of GMHC's clients by the mid-nineties were not white, and the agency provided training on "multiculturalism" to staff, questions persisted as to whether GMHC—or any one agency, for that matter—should be the preeminent agency to serve everyone affected by HIV and AIDS. Campbell noted that among AIDS service providers in New York, the expansion of GMHC to serve nonwhite, nongay communities "brings a lot of tensions for us that have more to do with issues of race and power in this country than they do with the fact that you're white and gay and I'm a heterosexual female."⁶⁶³

Black gay and AIDS activist George Bellinger, Jr., said, "You can't blame them completely," as he spoke of GMHC and other large AIDS groups founded by, and still perceived as "belonging to," white gay men despite racially mixed staffs and very high numbers of clients who are neither white nor gay. "You have to also blame the funding streams because they pick out the best

⁶⁶². Rev. Carl Bean, interview with author, Washington, DC, 16 November 1995.

⁶⁶³. Linda Campbell, interview with author, New York City, 28 April 1995.

VICTORY DEFERRED

proposals, and the evaluation of what looks the best. We fund them rather than the group that really knows the community and is struggling.”⁶⁶⁴

In fact, the struggle faced by the newer AIDS organizations founded by and for people of color in the 1990s was similar to that of the older “white gay” organizations. They also struggled with a lack of experience writing successful grant proposals, which often hindered their ability to compete with their more seasoned counterparts in the gay community. In an example too familiar to minority-run AIDS organizations, it was at least partly because of a lack of staff capable of writing a highly technical grant application that IMPACT-D.C., a Washington, DC organization that provided services to Black gay people with AIDS, missed its chance at a \$130,000 federal contract in 1994, according to Keith Fabré, the group’s deputy executive director.⁶⁶⁵

But this experience is not unique to AIDS organizations or to people of color; in the early years of the epidemic, it was familiar to the agencies established in the white gay community as well. In a 1994 article I wrote for *10 Percent* magazine about the competition for funds between “white gay” and people-of-color AIDS groups, I quoted Bill Freeman, then director of the National Association of People with AIDS, as saying, “It’s not correct to say that gay-identified organizations early on had capability; they didn’t. They were always on the brink of going out of existence because of fear, prejudice, outright discrimination,

⁶⁶⁴. George Bellinger, Jr., interview with author, New York City, 2 March 1995.

⁶⁶⁵. Lou Chibbaro, Jr., “IMPACT Misses Deadline: Three-Minute Delay Costs Group About \$130,000 in Federal Funds,” *Washington Blade* (6 May 1994), 1.

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and the constant challenge of fundraising. The minority community is now experiencing what the gay community experienced early on.”⁶⁶⁶

To attribute the expansion of the so-called white gay organizations to nothing more than a kind of plantation paternalism is to grossly simplify the situation. There certainly was often that sense that “We’ve been there, done that, and can either do it for you or show you how to do it our way.” But at least as forceful in the groups’ expansion was the pressure by funders—particularly the city, state, and federal governments—to require that the gay agencies serve everyone. Judith Johns, a former director of Howard Brown and at the time of our interview the director of AIDS programs for the city of Chicago, said, “What we found in Chicago is that many of our agencies that historically were considered gay are no longer designating themselves as gay.”⁶⁶⁷ Johns said that as grants and contracts became available to provide services to nongay, nonwhite people, the gay-identified organizations went after them—at first because no one else wanted them, but then because they were able to write the strongest proposals.

But Johns failed to mention the role that the city’s funding requirements played in forcing the gay groups to shift their focus. Frank Pieri explained it this way: “It’s kind of odd,” he said, “because here you’re doing not-for-profit, significant work. Nobody denies that who you’re serving needs the care; it’s not like you’re serving people who don’t need it. But you’re almost made to feel like you’re doing something wrong because you’re not all things to all people, or your mission is what your mission

⁶⁶⁶. John-Manuel Andriote, “The New AIDS War,” *10 Percent* (January/February 1994), 51.

⁶⁶⁷. Ibid.

VICTORY DEFERRED

has always been. Howard Brown has never changed its mission from gay and lesbian health care.” Pieri added, “Minority groups and women and children need care; I don’t deny that. What I’m saying is that I think the gay community has been lost in this. So many gay dollars are being donated to organizations that are losing touch with their gay and lesbian roots because the federal funding is not going there, the state funding is not going there, the city funding is not going there. You won’t get it if you say we’re just a gay and lesbian organization.”⁶⁶⁸

While there have been tensions over money in cities throughout the country between the older gay AIDS organizations and the newer agencies serving people of color, a situation developed in Washington, DC, during the summer of 1993 that was every bit as hot, sticky, and uncomfortable as the city’s summertime weather—and took the competition to a whole new level. While AIDS ravaged the nation’s capital (Washington still has the highest per-capita incidence of HIV and AIDS in the US, particularly among Blacks), the tensions between AIDS service providers reached a boiling point.

Those involved, or who wanted to be involved, in providing AIDS services battled one another with a fierceness that *Washington Post* columnist Richard Cohen said made the war in Bosnia “seem like TV’s old Nelson family.”⁶⁶⁹ The opponents were Black and white, and either openly or at least known to be (but denying they were) gay. Their weapons were crude but extremely hurtful: charges of racism, homophobia, and intimidation tactics that would rattle the steeliest nerves. The ostensible “prize” they were fighting for was a \$2 million AIDS services

⁶⁶⁸. Pieri interview.

⁶⁶⁹. Richard Cohen, “Federal Money for Racists,” *Washington Post* (29 July 1993), A25.

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contract funded by the federal government and channeled through the District's AIDS office.

The real issue dividing them, however, was the same issue dividing communities across the country: Who should provide AIDS services to the gay and bisexual men of color who account for such a disproportionately high percentage of the city and the country's AIDS cases. Should it be the "white gay" AIDS organization that had been providing services to gay and bisexual men for years? Should the funding be used to buttress the fledgling AIDS program of a minority-run agency? Or should the money go towards creating a new AIDS organization altogether?

The bickering between the white and people of color gay AIDS groups was not new. Then-Whitman-Walker Clinic director Jim Graham said, "The [District's] first AIDS controversy was racial." He explained that when the District government in 1983 awarded its first AIDS contract, "We spent the summer of 1983 arguing whether the money should go to Whitman-Walker Clinic or to some undesignated Black organization."⁶⁷⁰ That first contract was for \$17,500—pocket change compared to the millions now at stake. As the funding available for AIDS increased over the years, so did the decibel level of the arguments over who should get it. The only thing that plummeted in the city of escalating AIDS cases was the depth to which some would sink in trying to procure or protect their own slice of the AIDS funding pie.

When the AIDS epidemic began, Whitman-Walker had already been in existence for a decade. AIDS services were a natural extension of its work in the gay community. For its part,

⁶⁷⁰. Jim Graham, interview with author, Washington, DC, 30 August 1993.

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the city was only too happy to award its first contract—and many subsequent contracts—to the clinic. “Whitman-Walker took the city off the hook,” said Jane Silver, who at the time of the first contract award in 1983 was the AIDS adviser to the D.C.’s public health commission and later was the city’s first AIDS chief. “We were trying to know what to do while the clinic was serving patients,” she added.⁶⁷¹

Between 1983 and 1993, Whitman-Walker had become the District’s leading AIDS service provider by growing and expanding to meet the ever-increasing demands of the epidemic. While it started out as an essentially white gay organization, director Graham proudly pointed out that the clinic had become “multicultural.” Gay white men now made up less than a third of its staff, which in 1993 numbered nearly two hundred, and its clients were more than two-thirds Black and Hispanic. In 1992, Whitman-Walker opened a satellite clinic in Anacostia, an area of the city that is 96 percent Black. And in the fall of 1993, it opened the Elizabeth Taylor Medical Center, to provide primary care services to people with HIV. The center is located in the heart of the now-thriving Fourteenth Street NW corridor, though at the time of the opening the clinic was “pioneering” in what was then a rather seedy area.

In 1993, the District government decided that, instead of automatically awarding the AIDS services contract to Whitman-Walker, as it had done for a decade, it would invite competitive bids. But the District’s expectations were high after the tremendous return it had gotten on its investment in the clinic over the years. In fact, the requirements of the “soup-to-nuts” contract, as Graham described it, read like the clinic’s own service directory: primary care, medical evaluations, STD treatment, on-site HIV antibody testing, case management, referrals for at least

⁶⁷¹. Andriote, “The New AIDS War.”

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three thousand patient visits a year, dental and pharmacy services, legal services, and the training and supervision of at least fifteen hundred volunteers. Quite simply, no other organization in Washington, Black or white, could match Whitman-Walker in terms of AIDS experience, ability to deliver the services required by the contract, and skill at writing winning grant proposals. After all, none of them had the clinic's level of funding or years of building the kind of organizational infrastructure needed to support the level of services the city expected.

One organization emerged, however, represented by a belligerent and gay-baiting consulting group called URBAN (United Response to Black America's Needs), Inc. URBAN was formed by several Black gay men to go after the \$2 million contract after they left their jobs in Whitman-Walker's own grant-writing department, where they were privy to the clinic's funding information. URBAN's client, the Abundant Life Clinic, was run under the auspices of the Nation of Islam. Its director, Abdul-Alim Muhammad, was the Nation of Islam's "health minister" and a national spokesman for Louis Farrakhan, the controversial leader of the Black Muslim group known for his support of racial separatism, hateful views of whites, Jews, women, homosexuals—and his belief that AIDS is a "white plot" against the Black race. The involvement of the Nation of Islam in the city's AIDS funding dispute gave the issue "a whole new spin," as Whitman-Walker's Graham so understatedly put it.

When the city awarded the Abundant Life Clinic only \$213,000, about a quarter of the amount it had requested, URBAN went ballistic. The group's president fired off a vitriolic letter to the director of the city's human services department, which oversees its AIDS office, in which he claimed racial discrimination; demanded that the city's AIDS chief, pioneering lesbian health activist and longtime AIDS service provider Caitlin Ryan, be fired for what he claimed was her favoritism

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toward white gay groups, such as Whitman-Walker; and, for good measure, threatened to sic Louis Farrakhan on the District's then-mayor, a Black woman. Courtland Milloy, a Black *Washington Post* pundit, published a column about the situation that sent shock waves through the city's AIDS services community and further escalated the racial tension. In the column—later described as an “unfortunate event” by the *Post*'s ombudsman when it warranted an exceptionally long follow-up correction⁶⁷² and a two-part critique because of its many lapses in both fact and logic⁶⁷³—Milloy characterized Ryan as “a fierce lesbian warrior” who had turned the city's AIDS office over to a “loyal gay cabal.”⁶⁷⁴

In her own defense, Ryan told me that during her two years as D.C.'s AIDS chief, she had overseen a 93 percent increase in Ryan White CARE Act funding to minority-operated organizations—as well as a 542 percent increase to nonminority organizations, including Whitman-Walker, that served between 70 to 99 percent minority clients. She pointed out that, in view of the District's Black majority population, “It is important to realize that in a city like this, most public money goes to serve minorities,” regardless of the real or perceived skin tone of the service agency's staff.⁶⁷⁵

⁶⁷². Corrections, *Washington Post* (15 July 1993), A3.

⁶⁷³. Joann Byrd, “The Flawed Column,” *Washington Post* (25 July 1993), C6; Joann Byrd, “The Flawed Column (Part II),” *Washington Post* (1 August 1993), C6.

⁶⁷⁴. Courtland Milloy, “War on AIDS is Victim of Friendly Fire,” *Washington Post* (7 July 1993), D1.

⁶⁷⁵. Caitlin Conor Ryan, interview with author, Washington, DC, 21 August 1993.

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In this superheated atmosphere, Ryan was eventually fired from her job. Once she was effectively out of the way, URBAN organized a new coalition of primarily Black organizations to go after the \$2 million contract when the city decided to repeat the bidding process. Called the “Sankofa” (after a Ghanaian symbol representing the healing arts) Community Coalition of HIV/AIDS Services, the alliance included a number of the city’s leading minority-run organizations. URBAN announced on behalf of the coalition that Abundant Life Clinic would be its primary service provider. But newspaper headlines in the *Washington Post* and *Washington Blade* betrayed the sharp disagreements among the city’s Black gay AIDS service providers over whether Abundant Life could effectively serve Black gay men who represented more than half the AIDS cases in the D.C.’s Black community, in view of the antigay views of the Nation of Islam.⁶⁷⁶

URBAN published bizarre editorials and letters to the editor in the *Washington Blade*, disavowing any connection to the gay community and beating the same drum of racial separatism for which Farrakhan was known. In one, the group’s “chief of staff”—who refused to answer my faxed questions and repeated telephone calls after agreeing to be interviewed—wrote, “We are not allies of...‘gay liberation’ and don’t claim the ‘rainbow flag’ as ours. We are members of a community with a history in this nation rooted in struggle against white injustice, racism, and oppression.”⁶⁷⁷ Why the group published its diatribes in the gay newspaper remained a mystery. Trying to play the voguish game of out-victimizing other victims, URBAN was roundly condemned by both Blacks and whites.

⁶⁷⁶. Lou Chibbaro, Jr., “Black Gays Debate Abundant Life Role in AIDS Coalition,” *Washington Blade* (3 September 1993), 41.

⁶⁷⁷. Julian K. Tolver, “Fighting for African Americans’ Survival,” *Washington Blade* (17 September 1993), 41.

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When the District government finally stopped its hand-wringing a year later, it awarded the AIDS services contract to Whitman-Walker Clinic after all.⁶⁷⁸ While URBAN bitterly challenged the “legality” of the contracting process, others in the Black gay community recognized the need for conciliation and cooperation between Blacks and whites. Carlene Cheatam, cochair of the DC Coalition of Black Lesbians, Gay Men, and Bisexuals, said, “We have confidence the clinic, in receiving the award, will do its share of serving African-Americans who are affected by the disease.”⁶⁷⁹

Everyone in the early nineties, and still today, was trying to answer the question of who could best serve whom, whether gay and bisexual men of color should be served in a “gay” organization or an organization run by people of color who weren’t necessarily gay themselves. A continent away and many years after the growing pains as cities and organizations tried to respond to an ever-increasing epidemic, Caitlin Ryan still feels the pain of being caught in the wheels of racial tension that still fester in HIV service circles over which organization should receive how much to serve what slice of the community of HIV-positive “consumers.” What hurt most, said Ryan, now an internationally noted researcher on sexual minority youth, was how few others in the gay community publicly stood up for her. “I always stick up for the underdog,” she told me in 2010. “To have so few people stand up for me was really shocking.”⁶⁸⁰

⁶⁷⁸. Amy Goldstein, “City Giving AIDS Clinic \$1.2 Million,” *Washington Post* (16 June 1994), D1.

⁶⁷⁹. Andriote, “The New AIDS War.”

⁶⁸⁰. Caitlin Conor Ryan, telephone interview with author, 18 April 2010.

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Even when they weren't competing with gay community agencies, Black AIDS groups had a hard time generally in raising money among African-Americans. In a 1995 *New York Times* article, Minority Task Force on AIDS director Linda Campbell was quoted as saying, "I don't have a single Black major donor over \$1,000. There are no David Geffens in the Black community."⁶⁸¹ At least not among the Black gay people who—as white gay people have done among whites—lead the African-American community's efforts on AIDS. Geffen had recently donated \$1.5 million to God's Love We Deliver, the New York agency that provides meals to homebound people with AIDS, and \$2.5 million to GMHC.

As a result, the Task Force, like other minority-run AIDS organizations, was forced to rely on government funding for the bulk of its annual budget—which, as Dennis Altman warned in his book about community-based responses to AIDS throughout the world, is a precarious position to be in because of the potential for pressure to compromise the organization's identity. "It is necessary to be cautious about the embrace of the state," wrote Altman, "like that of the cobra, it can be fatal."⁶⁸² At the 1995 Gay Men of Color AIDS Summit, held in San Francisco, groups representing African-American, Latino, Native American, and Asian/Pacific Islander gay men of color resolved that organizations that are run by or serve gay men of color "must diver-

⁶⁸¹. Felicia R. Lee, "Blacks' Dollars Seem Scarce in AIDS Fight," *New York Times* (20 August 1995), 35.

⁶⁸². Dennis Altman, *Power and Community: Organizational and Cultural Responses to AIDS* (London: Taylor & Francis, 1994), 116.

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sify their funding base to ensure program flexibility and continued viability.”⁶⁸³

Describing the Black community’s hesitant response to AIDS, Campbell said, “We’re still at war with ourselves about AIDS in a way. What we see in the epidemic—like the drug use—reminds us of all the evils that have torn us apart. It’s not what we imagine ourselves to be in this country. I’ve been told Blacks give our money to other things: churches, Black colleges, fraternal organizations.” The late Keith Cylar, then codirector of Housing Works, a New York agency founded by ACT UP members to house people with AIDS, said he was having better luck raising money from blacks than the Task Force, but not much better. “It’s kind of like a lot of Black families have a cousin who is a drug addict, but you don’t embrace him,” he said. “And if I’m going to write a check to a cause, does it go to something that might kill me in ten years like AIDS, or to stopping stray bullets?”⁶⁸⁴

Such a question goes to the heart of much deeper racial and socioeconomic problems that are well beyond the ability of AIDS service organizations to solve and this book to address. But the effect of tensions that stem from those problems—distracting, even derailing, efforts to provide AIDS services to those who need them—has been a constant source of strain for everyone involved. Clearly there are no easy answers. But as questions about racial attitudes in America continue to be sorted out, even under the nation’s first African-American president,

⁶⁸³. National Task Force on AIDS Prevention, *Report on Standards As Set Forth at the Gay Men of Color AIDS Summit, August 31–September 3, 1995* (San Francisco: National Task Force on AIDS Prevention, 1995).

⁶⁸⁴. Lee, “Blacks’ Dollars Seem Scarce in AIDS Fight.”

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other questions demanded answers by AIDS service organizations and the for-profit businesses that were established to raise money for them. The willingness (or lack of it) of AIDS fundraisers to account for the proceeds of their efforts brought its own challenges to the continued viability—and credibility—of all AIDS organizations.

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As the AIDS industry grew and became more professional because of funding from the Ryan White CARE Act, another industry grew up alongside it. From the earliest events organized by volunteers the walkathons, dances, silent auctions, and so on—emerged for-profit companies run by entrepreneurial former volunteers whose business was raising money for AIDS. Just as AIDS service organizations dislike the suggestion that their self-perpetuation is at odds with their original mission of putting themselves out of business by ensuring that sensitive HIV services are “mainstreamed,” these well-paid pros responded angrily when asked to account for the money they spent on sometimes outrageous overhead costs. But like the AIDS service providers, their discomfort with being scrutinized by the gay community that so generously funded AIDS services was necessary if they expected to have continued support.

During the 1994 “Stonewall 25” events commemorating the Stonewall uprising in New York City, the usually successful DIFFA lost \$30,000 on a series of sixteen parties called “Out in New York '94” that it cosponsored with Broadway Cares/Equity Fights AIDS and *Out* magazine. The group had anticipated profits of \$1 million. “There were just too many damn events,” said DIFFA director Rosemary Kuropat, who left the organization a year later. “I think our community perceives itself as sort of having an insatiable desire to party. There was too much going on.”⁶⁸⁵ To cope with the actual and projected losses, DIFFA

⁶⁸⁵. Peter Frieberg, “DIFFA Loses \$30,000 on Stonewall 25 Fundraiser,” *Washington Blade* (12 August 1994), 21.

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laid off six employees, postponed salary increases, and sought voluntary pay cuts of up to 25 percent.⁶⁸⁶

AmFAR, the wealthiest national AIDS organization in the country, saw its budget shrink from a high of \$24.8 million in fiscal 1993 to a fiscal 1996 budget of only \$16 million. In a press release, AmFAR president Mervyn Silverman said, "It is becoming increasingly difficult to raise money for AIDS research programs because of growing complacency and a sense of resignation about the epidemic."⁶⁸⁷

When the AIDS Action Foundation, the financial muscle behind AIDS Action Council, the Washington, DC lobbying group, reported a drop of \$342,000 in 1993 donations, then director Dan Bross told the *Washington Blade*, "People are getting tired and getting burned out on AIDS issues. We're thirteen years into the AIDS epidemic. What we're seeing from a lot of AIDS organizations is that it's increasingly difficult to raise money."⁶⁸⁸

What was happening? AIDS, which had gone from being the gay community's private burden to become a more than \$1 billion-a-year publicly funded federal program and cause célèbre, was, once again, having trouble attracting private dollars. In an article about the challenges to gay and AIDS groups in raising money, *Outlines*, a Chicago gay community newspaper, noted

⁶⁸⁶. José Zuniga, "Face of AIDS Groups Changes," *Washington Blade* (21 July 1995), 1.

⁶⁸⁷. José Zuniga, "AmFAR Closes Rockville Office: Budget Woes Force Layoffs for Nation's Largest AIDS Group," *Washington Blade* (16 June 1995), 6.

⁶⁸⁸. Aras van Hertum, "AIDS Action Foundation's Donations Drop \$342,000," *Washington Blade* (8 July 1994), 27.

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that corporate givers were more interested in other social service programs than in AIDS. While foundations are often good sources for seed money to start a new project, they balk at paying the operating expenses of an established but still-struggling organization. High overhead costs eat up the profits of fundraising benefits. And finally, said the article, "Individual donors, long the lifeblood of gay and AIDS-related organizations, are feeling the tug of literally dozens of organizations vying for the attentions of their wallets."⁶⁸⁹

Therein lies the rub, said Michael Seltzer: There were now far too many AIDS organizations vying for the same limited pot of private dollars. For him, the solution was a large, broad-based national AIDS organization that represents all the voices of people affected by HIV/AIDS, and has the integrity of representing everyone affected as a large, visible force—just like Planned Parenthood or the Children's Defense Fund." Seltzer contrasted the multitude of organizations throughout the country providing some kind of AIDS services with the single organization associated with fighting another, earlier epidemic. "In the thirties," said Seltzer, "there were not all these multiple organizations concerned with polio; there was one national organization with local chapters. And guess what? They beat polio. Everyone in the U.S. knew that polio equaled the March of Dimes."⁶⁹⁰

A survey by the American Association of Fund Raising Counsel, Inc. (AAFRC) estimated that, in 1992, between \$575 million to \$850 million of privately raised money went to AIDS

⁶⁸⁹. Jane Lowers, "The Funding Crunch: AIDS, Gay and Lesbian Organizations Compete for Limited Resources," *Outlines* (June 1995), 16.

⁶⁹⁰. Seltzer interview.

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causes. This seemingly large amount of money paled in comparison to, say, the \$1.4 billion raised by the Salvation Army in 1995 alone. In the mid-nineties, a scandal in the national office of the United Way and other factors suppressed Americans' charitable impulses. Boston's *Bay Windows* noted, "Fundraising experts blame a range of causes: skepticism about waste and fraud in larger charities, uncertainty about the economy, and a 'compassion fatigue' that burned out potential donors. AIDS fundraisers say this burnout has a new terrible dimension for them: Many of their strongest advocates and donors in the gay community have died. Others have given all they can."⁶⁹¹

Still others had begun to question just where, exactly, the money they gave to help fund AIDS services was going. In 1995, *POZ* magazine published its first assessment of AIDS fundraising. What it revealed was jarring. Kiki Mason, a journalist who covered parties and served as a publicist and event planner for New York City's Community Research Initiative on AIDS (Mason died of AIDS on June 19, 1996), noted in his hard-hitting article "Black Tie Lies" that the money-losing parties during Stonewall 25 were neither the first—and were hardly the only—AIDS fundraising fiascos.

The *Los Angeles Times* reported on an AmFAR fashion show that cost \$715,000 and raised \$750,000—not exactly efficient fundraising. And despite its claims of fundraising efficiency, DIFFA was spending 50 percent of the money it received from events to produce them. In contrast, Broadway Cares spent only 8 percent of the nearly \$2 million it raised in 1994 on event production. As Mason concluded, "AIDS service organizations have to make themselves responsible to the communi-

⁶⁹¹. Fred Bayles, "AIDS Organizations Feeling the Brunt of General Public's 'Compassion Fatigue,'" *Bay Windows* (10 August 1995).

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ty. They must begin dissuading mounting fears by coming clean with their figures. If they have nothing to hide, they have nothing to fear.”⁶⁹²

It wasn't, however, only the AIDS service organizations that needed to come clean and be held accountable. What Mason called a “shadow industry” had grown up to raise money exclusively for AIDS. Now professionals ran even the AIDS walks. And the costs merely to produce the events were, in some cases, hundreds of thousands of dollars more than the early AIDS fundraisers ever made. Like AIDS services, fundraising for AIDS became a big business. But for years few questioned the disposition of the money raised in the walks and dances and, particularly, the AIDS rides. Those raising money for AIDS were seen as doing “God’s work,” and so, apparently, were accountable only to a heavenly authority. More earthly minded people, however, began to ask, “How much of the money I contribute actually goes to the AIDS service providers for which it is ostensibly raised? How much goes to cover the ‘overhead’ of producing the event and paying the salaries of the full-time staffs? Finally, how much of it lines the pockets of the for-profit producers of the event?”

Was it reasonable for D.C.’s Whitman-Walker Clinic to spend \$450,000 to earn \$2 million? That was what the clinic expected to spend on and earn from its 1996 AIDS walk. For the first time, Whitman-Walker had hired a group called Walk the Talk Productions, a Los Angeles-based firm run by AIDS walk organizer Richard Zeichik. Zeichik and former partner Craig Miller cofounded Miller, Zeichik and Associates, which produced the first AIDS walk in the city of Los Angeles in 1985. The agency continues to produce walks in a number of cities.

⁶⁹². Kiki Mason, “Black Tie Lies,” *POZ* (February/March 1995), 48.

VICTORY DEFERRED

Whitman-Walker laid off two of its own staff to make way for Zeichik, who would be paid an “agency fee” of \$65,000 for six months of full-time work. That’s well over \$10,000 a month simply to plan the AIDS walk, that for the previous nine years had been organized by Whitman-Walker staff and volunteers.⁶⁹³

By 1996, the AIDS bike rides had become a full-fledged moneymaking industry in their own right. There were rides not only from San Francisco to Los Angeles, but also from Boston to New York, Philadelphia to Washington, DC, Minneapolis to Chicago, and Orlando to Miami. The rides were promoted by the makers of Tanqueray gin and vodka, whose rascally character, “Mr. Jenkins,” touted both the rides and the liquor in clever print advertisements in magazines, aimed primarily at the gay community and young people.

Paid staff of the 1996 Philadelphia to Washington, DC AIDS Ride drummed up contributions by giving pep talks and showing a tear-jerking promotional video in the homes of people who had signed up to ride. The message repeatedly was to “give the riders the experience of their lives” by donating enough money—fairly large contributions were strongly encouraged. Underlining the fact that the ride was more than just an effort to raise money for AIDS services by welcoming all who wanted to participate, each rider—as it were a proxy for the actual contributors—was required to raise at least \$1,400 if they hoped to enjoy the “once-in-a-lifetime” experience offered by the AIDS ride. Riders in the San Francisco to Los Angeles ride had to generate \$2,500 each.

In the Philly-to-D.C. ride, 1,901 riders raised a gross of \$4.5 million. After the congratulations to the returning “heroes” who

⁶⁹³. Sue Fox, “Consultant Producing AIDSWALK 1996,” *Washington Blade* (15 December 1995).

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had ridden from Philadelphia to Washington, D.C., had died away, some of the participants and sponsoring organizations began to ask bottom-line questions about the efficiency of the ride's actual fundraising. In a letter to the editor in the *Washington Blade*, published shortly after the ride, a rider named James. F. Smith wrote, "Of major concern to me and many other riders I spoke with was the production cost." He described the large paid staff, frequent mailings to the riders, and rented (as opposed to donated) vehicles to accompany the riders as examples of what seemed to add up to excessively large overhead expenses. Smith continued, "I am sure I will have several critics who will, as usual, scream about my questions, and argue that the event is totally justified and worthwhile at any cost. It is not. Cost containment is the first and primary goal to funnel the maximum cash to needy organizations."⁶⁹⁴

When Pallotta and Associates finally released figures after considerable delay, the AIDS organizations in Philadelphia were told they would share a total of \$330,740 from the \$1,661,173 raised by the Philadelphia contingent of 786 riders. This meant that seventy-nine cents of every dollar raised by the Philadelphians went to "overhead"—including \$417,628 for staff salaries and another \$180,000 in "production fees"—to cover Philadelphia's share alone. Washington fared somewhat better. Its 1,300 riders pulled in \$3,034,840, of which \$1,565,544 was eventually split between Whitman-Walker Clinic and Food and Friends, a meal delivery program for people with AIDS. Still, this meant that for the DC contingent forty-eight cents of every dollar raised went to "expenses."⁶⁹⁵ The organizations were

⁶⁹⁴. James F. Smith, "Bottom Line Questions," *Washington Blade* (5 July 1996), 29.

⁶⁹⁵. Lou Chibbaro, Jr., "Philly Groups Pull Out of AIDS Ride," *Washington Blade* (13 September 1996), 5.

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grateful for the money, and praised the ride without qualification, giving no public indication that they were concerned about the high cost of raising it.

In April 1996, the Pennsylvania attorney general launched an investigation of the Philadelphia–D.C. AIDS Ride, when AIDS groups in Philadelphia feared that the cost to produce the ride would eat up a considerable portion of the money they raised.⁶⁹⁶ After the ride, Dan Pallotta, founder of Pallotta and Associates, remained mysteriously “out of the country” and didn’t return phone calls to concerned AIDS organizations and the media scrutinizing the situation. When the company finally released the figures, it did so with a volley of blame for the Philadelphia AIDS groups themselves. Pallotta said there were “too many” AIDS organizations in the city, “fighting with one another over the shrinking pie, instead of coming together to find solutions.” What he failed to address, however, was why the “pie” itself had shrunk so drastically. An editorial in *Philadelphia Gay News* observed that the words “accountability and arrogance...come to mind” in reviewing Pallotta and Associates’ preliminary figures. It concluded, “Maybe [Philadelphians] expect people and organizations to take responsibility for their actions. Maybe Philadelphia and the AIDS Ride are incompatible in that way.”⁶⁹⁷

When all was said and done, the AIDS groups in Philadelphia had pulled out of the AIDS Ride for 1997. Within weeks, Pallotta and Associates were advertising a 1997 ride to

⁶⁹⁶. Scott A. Giordano, “Pa. Attorney General Began Ride Investigation in April,” *Philadelphia Gay News* (30 August–5 September 1996), 14.

⁶⁹⁷. Editorial, “A Few Words About the AIDS Ride,” *Philadelphia Gay News* (30 August–5 September 1996), 13.

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begin in a then-undetermined site in central North Carolina and terminate in Washington. This time only the groups in Washington would benefit. "As a rider in the Washington, D.C. AIDS Ride Presented by Tanqueray, you can participate in the most successful AIDS fundraising effort in history," promised the ad for the reconfigured ride.⁶⁹⁸ Of course the ad didn't reveal that overhead costs, to be borne by the D.C. groups alone, were expected to be even greater in 1997.⁶⁹⁹

As the 1997 AIDS rides got underway, the bad press continued to mount. In April, the Pennsylvania state attorney general concluded his yearlong investigation into the 1996 Philadelphia to Washington ride. Pallotta and Associates, together with three of the Philadelphia AIDS organizations that participated in the 1996 ride, were fined \$134,000 for misleading the public over how much of the money raised from the Philadelphia portion of the ride would go to the charities as opposed to "overhead." The agreement reached between the attorney general and the organizations charged that the organizations had "misrepresented" to the public that they expected to earn a 60 percent profit margin for the event, even after "unforeseen circumstances" before the ride that they knew would make that kind of profit impossible. Under the settlement agreement, the three AIDS organizations each paid \$8,000, and Pallotta and Associates paid \$110,000. Attorney General D. Michael Fisher

⁶⁹⁸. Advertisement in *Washington Post*, "Weekend" (27 September 1996).

⁶⁹⁹. Lou Chibbaro, Jr., "Philly is Bumped From AIDS Ride," *Washington Blade* (27 September 1996), 5.

VICTORY DEFERRED

said his office would donate \$112,000 of the fines to the AIDS organizations—though not to the ones that paid the fines.”⁷⁰⁰

An investigative article in a Minneapolis newspaper in July 1997—aptly titled “Taken for a Ride”—noted that seventeen hundred bicyclists were expected to ride in the second Twin Cities to Chicago AIDS Ride, raising more than \$2 million. Yet public documents filed by the AIDS organizations that were to benefit from the ride indicated that a mere 31 percent, or \$627,843, would actually reach the organizations after “expenses.” After similar “expenses”—including \$403,136 for salaries and commissions, and 16 percent of the money going toward ambiguous “other” costs—only 38 percent of the more than \$2 million raised in the 1996 Twin Cities ride actually reached the AIDS service organizations. In contrast, Minnesota’s Charities Review Council noted that the Minnesota AIDS Project’s annual AIDS walk spent only 7 percent on overhead costs. A bikeathon by Habitat for Humanity typically spent 20 percent of its proceeds on overhead. A ride coordinator for Pallotta and Associates was quoted as saying that the “personal life-changing experiences” of participating in the rides made the AIDS rides unique. But Tom Sullivan, of Pro Events International, who organized the Habitat for Humanity ride and other biking-for-charity events in Minnesota and nationally, called the AIDS ride expenses “simply ludicrous.”⁷⁰¹

In Florida, six AIDS service organizations in 1997 severed their ties with Pallotta and Associates after receiving only eighteen cents of every dollar raised in the Florida AIDS Ride for

⁷⁰⁰. Lou Chibbaro, Jr., “AIDS Ride Organizer to Pay Fine,” *Washington Blade* (25 April 1997), 1.

⁷⁰¹. Sue Rich, “Taken for a Ride,” *Minneapolis City Paper* (2 July 1997), 8.

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two years in a row. The remaining eighty-two cents on the dollar went to “overhead.” John Weatherbead, an official with CenterOne, a Fort Lauderdale AIDS organization involved with the ride, said the Florida groups were considering organizing their own bike benefit ride in 1998.⁷⁰² And in Philadelphia, plans were underway for “Ride for Hope,” which organizers said wouldn’t be as elaborately produced as the AIDS rides. “Everything will be very low-key and grassroots,” said Nurit Shein, director of Philadelphia Community Health Alternatives, the sponsor of the event. “Expenses will be kept to a bare-bones minimum.”⁷⁰³

Pallotta and Associates’ “national director for logistics,” Kevin Honeycutt, told the *Washington Post* that the company was forthright with AIDS organizations about the risks and benefits of being involved in the AIDS rides. “We come to an agreement with our client,” he said, “about what is an achievable—sometimes aggressive but achievable—registration number and performance rate. We investigate what the market can pull, how much the incidence of HIV is in the market, and we look at how we can market the ride to recruit enough riders so it’s a win-win for everyone.” The *Post* noted—apparently this was meant to assuage critics of Pallotta and Associates—that “public records confirm that Pallotta, thirty-six, lives in a modest home and does not own an airplane, boat, or exotic car.”⁷⁰⁴

⁷⁰². Lou Chibbaro, Jr., “Florida AIDS Groups Drop Promoter,” *Washington Blade* (13 June 1997), 16.

⁷⁰³. Timothy Cwiek, “PCHA Plans ‘Low-Key’ Bike Ride as Fund-Raiser,” *Philadelphia Gay News*, 20–26 June 1997), 8.

⁷⁰⁴. Rick Weiss, “Questions on Overhead Dog AIDS Bike-Trip Organizer,” *Washington Post* (9 June 1997), A6.

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The 1997 North Carolina to Washington AIDS Ride generated \$3.8 million. Whitman-Walker Clinic and Food and Friends, the two DC groups to benefit from the ride, received about \$1 million each. The remaining money—nearly \$1.7 million, forty-four cents of each dollar raised—went to “overhead.”⁷⁰⁵ Just as the ride got underway, an AIDS service group in Raleigh, NC, pulled out of plans for a 1998 ride and another group announced it would probably not be able to pay Pallotta and Associates’ up-front \$180,000 fee. A number of riders reported that they had difficulty getting contributions from people who were upset that so much of their contribution would be going to the ride’s overhead costs.

Could anyone *really* be surprised? At a time when American charitable giving had been rocked by scandals and embezzlement at mainstream philanthropies, why did AIDS ride organizers believe their particular effort was the exception? When they weren’t coldly calculating about “markets” and “what is achievable,” like Pallotta and Associates’ Kevin Honeycutt, they waxed rhapsodic about the public relations value and “life-changing experiences” of the rides. But they didn’t seem to understand that even generous people expect accountability where their money is concerned.

The days of giving money for AIDS services that wound up lining the pockets of those profiting off of AIDS were numbered. What about the Ryan White CARE Act funding for AIDS services at the time (more than \$2 billion a year today)? It is paid for with our tax dollars—yet, as Larry Kramer always pointed out, we pay twice for AIDS services when we donate money. Now we were being asked to pay for hefty salaries and bonuses for profiteers. What about trying more cost-efficient means of

⁷⁰⁵. Christopher Jones, “AIDS Ride Distributes \$2 Million to Charities,” *Washington Blade* (12 September 1997), 1.

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fundraising than the special events, like the AIDS rides that make some people feel good and other people rich? Surely not all those volunteers who used to organize the bikeathons and walkathons at minimal cost had become money-grubbers?

For years, AIDS organizations relied on what Paula Van Ness called “black-tie bake sales,” special events—the walks, the dance-a-thons, the fashion and drag shows, and the AIDS rides—to raise substantial portions of their annual revenue. As the epidemic stretched on, though, they had to develop more fundraising savvy and turn to more traditional forms of fundraising, such as planned giving, estate bequests, and the cultivation of major donors who renew their pledges each year. Like many other nonprofits, they also had to learn to use direct marketing to target fundraising solicitations at individuals known by traits such as their spending habits and magazine subscriptions to be sympathetic to the AIDS cause.

Among gay and AIDS groups, *POZ* magazine founding publisher Sean Strub has been looked to as a guru of direct mail fundraising because of his impressive success in making money for himself as well as a number of causes and organizations he supports. In 1996 alone, Strub anticipated gross earnings of \$11 million from the four enterprises that comprised his Strubco. Drawing on his “national community master file” of six hundred thousand names, Strub helped to raise \$400,000 for GMHC from one fundraising appeal alone, and contributed heavily to ACT UP/New York’s \$1 million budget at the height of the protest group’s short but dazzling life. Strub was feeling weary of the inefficiency and lack of accountability among AIDS organizations and those raising money for them. As he put it, “In general, I’m kind of disillusioned with the institutionalization

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of the community organizations. Dollar for dollar, I don't think they're as effective today as they were ten years ago."⁷⁰⁶

Yet gay community dollars throughout the 1990s continued to flow into AIDS organizations and high-priced fundraising events like the AIDS rides. As the epidemic stretched into the foreseeable future, some in the community began to demand an accounting of how their contributions were being used—and who, exactly, was benefiting from them. It is an understatement to say that gay people have been extremely generous with their time, talents, and money in the interest of caring for people with HIV and AIDS.

But as the epidemic continued to move beyond the gay community, and as organizations that were created by gay people when AIDS was an overwhelmingly gay problem continued, rightfully, to serve all who were affected by the disease, the nagging of one question became louder with each fundraising event and direct mail solicitation: Why should gay people, estimated at most to be 10 percent of the population, underwrite the costs of AIDS services for everyone? Certainly the AIDS service organizations originally founded by and for gay men went far beyond the call of duty by serving many others affected by HIV. But should gay community money continue to pay for services for nongay people? At a minimum, weren't there more efficient ways of raising money than, say, an AIDS ride that consumed as much as 82 percent of the money raised, as it did in Florida?

Michael Seltzer said, "The story that hasn't been told about our community is that the philanthropic, charitable response of

⁷⁰⁶. Peter Frieberg, "Mixing Politics and Profits: Entrepreneur Sean O'Brien Strub Says He's an Activist at Heart," *Washington Blade* (19 July 1996), 14.

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our own people has been overwhelming.” He added, however, “We, our lesbian and gay community, have carried this responsibility almost singlehandedly—the entire burden of addressing the major health threat of the last part of the twentieth century worldwide. We can’t do it alone anymore.”⁷⁰⁷

“Alone” is precisely how gay people have had to face the AIDS crisis too much of the time. “Alone” is never so solitary a state as it is in facing death. Behind the appeals for money and support, behind the politics and posturing—behind everything gay people have done in response to AIDS—there is the death. Gay people have been so extraordinarily charitable because we have been hit so extraordinarily hard by the massive numbers of gay men who have died from “complications associated with AIDS.” More than anything else, gay America has come of age by being forced to confront mortality, by being cruelly disabused of the illusion that sustains Americans who foolishly believe their diets, pills, plastic surgeries, and transplants will somehow keep the Grim Reaper at bay. Oddly, in confronting death at such a young age, many gay people learned the “secret” of living while we are alive—something most people don’t learn, if ever, until old age. What an expensive gift.

⁷⁰⁷. Seltzer interview.

PART 9

IN MEMORIAM

*Here pause: these graves are all too young as yet
To have outgrown the sorrow which consign'd
Its charge to each ...*

PERCY BYSSHE SHELLEY, *ADONAIS*

AIDS has devastated gay people. Fortunately, not even all the death and destruction to our community could obliterate our gay spirit that has helped us and our forbears throughout history to survive regular attacks of one kind or another. Yet many gay people struggled to believe that their losses mattered, that their grief was as real and every bit as significant as that of nongay people. The politics of mourning were as volatile in gay America as the politics of AIDS were in Washington. Refusing to accept the social message from our fellow Americans that our lives and loves somehow didn't matter, gay people insisted that our losses would indeed count. With creativity, humor, and a great deal of pain, we confronted the nation with the fact that we were suffering—and it didn't seem to care. Our mourning often turned to militancy as we raged against the darkness—and often against those who hid in the darkness of their own minds from what was happening in their beloved America.

THIRTY-TWO

On Friday the thirteenth of March 1987—the morning after ACT UP was officially created at a meeting at New York’s Gay and Lesbian Community Center⁷⁰⁸—the *Wall Street Journal* reported on page one, “AIDS has been cruel to Greenwich Village and its homosexuals.”⁷⁰⁹ AIDS was devastating the Village. The *Journal* noted that at least seven hundred of the more than nine thousand AIDS cases in New York at that point were reported among the Village’s estimated eighteen thousand homosexuals. One in every twenty-five gay men in the Village was living with or had already died of AIDS. Life continued in the Village. “But,” noted the *Journal*, “More young men these days get around with the help of canes or walkers. Wartime metaphors spring to people’s lips. And the keeping of lists has become a grotesque commonplace.”

⁷⁰⁸. Larry Kramer, *Reports from the holocaust* (New York: St. Martin’s Press, expanded and reissued 1994), 137. Kramer notes that two days after his speech on Tuesday, 10 March 1987, “The gay grapevine functioned remarkably well, for some three hundred or more showed up that Thursday night, and the result was the establishment of ACT UP—the AIDS Coalition to Unleash Power—an ad hoc community protest group that, originally, was pledged to concentrate on fighting for the release of experimental drugs.”

⁷⁰⁹. Ellen Graham and Roger Ricklefs, “AIDS Has Been Cruel to Greenwich Village and Its Homosexuals,” *Wall Street Journal* (13 March 1987), 1.

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Police officials reported that weekend pedestrian traffic on Christopher Street—the street that gave birth to and symbolized Gay Liberation—had dropped as much as 40 percent. Rob Kilgallen, owner of a candle shop on the street, said that because of the withering of the street's life he now closed shop at eight rather than ten or eleven as he used to do. He noted that on the same street the owners of a flower shop, card shop, and a store selling movie memorabilia had already died. And at least three gay bars in the Village had closed for lack of business.

While AIDS laid siege to the Village and other gay communities around the nation that March, the Reagan administration announced that it was finally forming a commission to look into the disease that by then had grown to 51,000 cases in 113 countries—six years into the epidemic.⁷¹⁰ AZT was reported that month to halt the spread of the virus in the body. And on the last day of the month, polio vaccine inventor Jonas Salk successfully mediated a settlement in the rancorous debate between the French and Americans over who actually discovered the AIDS virus. One of the biggest steps forward in the nation's halting response to AIDS also was made that month in the Supreme Court's decision in *School Board of Nassau County v. Gene H. Arline*. The court ruled that someone with a contagious disease—schoolteacher Arline had recurring tuberculosis—is considered “handicapped” under federal antidiscrimination laws. Urvashi Vaid, then the media director for the National Gay and Lesbian Task Force, said, “Now people with AIDS will have a leg to stand on.”⁷¹¹

⁷¹⁰. Randy Shilts, *And the Band Played On* (New York: St. Martin's Press, 1987), 589.

⁷¹¹. Diane M. Ginaelli, “High Court Ruling Gives Basis for AIDS Bias Suits,” *American Medical News* (13 March 1987), 1.

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In San Francisco that spring, Cleve Jones and a group of strangers met in the Castro district to discuss their idea for creating a memorial quilt, a huge patchwork whose individual three-by-six-foot panels would commemorate those who had succumbed to AIDS. Jones said, “We wanted to illustrate the enormity of the AIDS crisis by revealing something of the lives behind the statistics, to provide evidence of the calamity that we saw unfolding.”⁷¹² The Castro at the time was shrouded in gloom thick as the city’s famous fog. Men speak today of the “dark years” in the mid-eighties, when so many gay-owned businesses in the Castro closed—sometimes because the owner had died, other times because the clientele were dead. Thousands would gather for candlelight vigils, then quickly disperse afterward, returning to the safety of home. The hilarity that had sparkled in the air and sparked the westward migrations of gay men to the city in the seventies had given way to a stunned, mournful silence.

In an op-ed article in the *New York Times* published on Christmas Eve 1994, San Francisco novelist Fenton Johnson captured the shattering losses he and other gay men had suffered, as well as their attempts to make some kind of sense of so much senseless destruction of their lives and community. “The intertwining of death and life is something I have been given much cause to contemplate across a decade of helping friends greet their deaths,” he wrote.⁷¹³ A 1994 report by the San Francisco public health department predicted that by 1997,

⁷¹². Cleve Jones, in Joe Brown, ed., *A Promise to Remember: The NAMES Project Book of Letters* (New York: Avon Books, 1992), vi.

⁷¹³. Fenton Johnson, “Death Into Life,” *New York Times* (24 December 1994).

VICTORY DEFERRED

more than 26,700 AIDS cases would have been diagnosed in the city, mostly among gay and bisexual men. An additional 18,000 gay men would be infected with HIV, though not yet diagnosed with AIDS. All told, the first sixteen years of the epidemic would find 45,000 residents infected with HIV, diagnosed with or dead from AIDS—nearly two-thirds of the estimated 75,000 gay men in San Francisco at the start of the epidemic.⁷¹⁴

Considering these numbers, it seemed nothing short of astounding when the *San Francisco Examiner* in January 1995 noted in a page 1 story that AIDS no longer ranked among the nation's urgent worries.⁷¹⁵ Then again, a local right-wing “shock jock” in San Francisco—one of the world's hardest-hit cities, and the city famous for its compassionate handling of the AIDS crisis—was still calling for the quarantine of people with AIDS.⁷¹⁶ In some ways it seemed the only thing that had really changed from the early years of the epidemic was the now-huge numbers of deaths. Since the earliest calls like that of this

⁷¹⁴. *Projections of the AIDS Epidemic in San Francisco: 1994–1997* (San Francisco: Department of Public Health, 15 February 1994). Noted in Eric Rofes, *Reviving the Tribe: Regenerating Gay Men's Sexuality and Culture in the Ongoing Epidemic* (New York: The Harrington Park Press, 1995), 169. Rofes explained that he arrived at the figure of 75,000 gay men in San Francisco in 1980 by estimating the city's lesbian and gay population at 20 percent of the city's total 1980 population of about 750,000, divided equally between lesbians and gay men.

⁷¹⁵. Lisa M. Krieger, “AIDS Loses Urgency in Nation's List of Worries,” *San Francisco Examiner* (29 January 1995), 1.

⁷¹⁶. Dennis Conkin, “AIDSphobia Hits the SF Airwaves,” *Bay Area Reporter* (26 January 1995), 1.

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troglodyte, nearly 15,000 San Franciscans had died of AIDS—almost all of them gay men.

As we sat outdoors on the last night of January 1995, at the Castro area's Café Flore, Johnson offered a poignant image from his own life that provided a glimpse of what life was like now for so many in the city by the bay—and far beyond. Strains of "Where the Boys Are" drifted across the cool night air from a nearby bar. In a Kentucky-accented voice as resonant as his prose, Johnson told me, "No one I knew in San Francisco around 1978 to 1980 is alive. That was when I first came to the city, and first came out." Although not HIV-positive himself, Johnson gave voice to the speechlessness of the horrors so many of us had witnessed. He described men who had renovated houses in the city's worst neighborhoods, just for the experience. "It was immaterial to them whether the house had any value ten years from now because they're not thinking in terms of ten years from now." Not only was it painful to witness, but it also shook up one's personal moral categories. Johnson explained, "You talk about lessons and grace and words like that, then you come face to face with someone who is talented and handsome and sweet and charming and intelligent and clearly a wonderful force in society and you learn they're grappling with this terrible thing. It really changes your ability, our ability, to find things like grace and lessons and joy—those necessary facts of life."⁷¹⁷

"April is the cruelest month," wrote T.S. Eliot in *The Waste-land*, "breeding/lilacs out of the dead land, mixing/memory and desire, stirring/dull roots with spring rain." The cruelest month in 1994 claimed the life of my own former lover, friend, and influential AIDS lobbyist Bill Bailey. It also claimed the life of John

⁷¹⁷. Fenton Johnson, interview with author, San Francisco, 31 January 1995.

VICTORY DEFERRED

Preston, a former editor of the *Advocate* and a prolific author. In an anthology of reflections on AIDS that Preston edited, he captured in one sentence the shock, bewilderment, and bereavement that had descended upon America's gay communities by the late eighties. Describing his reaction to the unexpected news of the death of one of his own first loves, Preston wrote, "Now he was gone, and it wasn't just that he was gone, but that all these men I loved were dead and their connection with me was left hanging in the hair, their spirits unresolved, the possibilities left unrealized."⁷¹⁸

Eric Rofes said the gay community had become a "death-saturated culture." He noted that most gay men, when asked about the impact of the epidemic on their lives, naturally responded by counting the number of friends and lovers they'd lost. But our losses went, and still go, to the very depths of our being as gay men. As Rofes saw it, "[F]or many gay men, the epidemic has mutilated our identities, profoundly warping sexuality and intimate relations, and reaffirmed bigoted subconscious linkages between homosexuality and contagion."⁷¹⁹ The loss of life the community suffered was appalling. But how do you measure the loss of so much joy and affirmation and possibility that were among the legacies of Stonewall?

"In modern times, no other single constituency has lost so many as a result of epidemic loss," observed English writer Simon Watney. "Outside of wartime or great famine, mortal illness and death on this scale is unknown, marking our experience as

⁷¹⁸. John Preston, ed., *Personal Dispatches: Writers Confront AIDS* (New York: St. Martin's Press, 1988), xv.

⁷¹⁹. Rofes, *Reviving the Tribe*, 23, 29.

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unique.”⁷²⁰ Of course the experience of suffering and loss is not unique to gay people. But in terms of the sheer volume of sickness and death—of mostly young people—the experience of gay Americans was unprecedented, particularly in an age when we thought medical science had virtually conquered infectious disease. As Sandra Jacoby Klein, a therapist in Los Angeles who has worked with bereaved gay men since the early eighties and is the author of *Heavenly Hurts: Surviving AIDS-Related Deaths and Losses*, has put it, “There is simply no equivalent to this experience in the nongay community.”⁷²¹

Besides the loss of life itself, the deaths from AIDS of gay and other men have taken a statistical toll. The *New York Times* reported in 1996 that “despite two world wars, the Depression and epidemics, nothing in this century has affected the life expectancy for New Yorkers as greatly as AIDS.” The city’s cumulative 81,500 AIDS cases at the time of the article’s publication—80 percent of them among males—had compressed the average life expectancy of males born in New York City, even as the average life expectancy for women in the city continued to rise. Just behind the city’s leading killers, heart disease and cancer (whose rates declined between 1980 and 1990), AIDS had “become so pervasive in New York City that it is affecting the statistical chance of babies and men under forty to make it to old age, because AIDS mostly kills men in their thirties, while the other diseases kill older men.” In a grim twist on New York’s penchant for starting national trends, the *Times* noted that simi-

⁷²⁰. Simon Watney, “Acts of Memory,” *Out* (September 1994), 92.

⁷²¹. Sandra Jacoby Klein, “AIDS-Related Multiple Loss Syndrome,” *Illness, Crisis and Loss* 4 (1994): 15.

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lar trends were likely in other cities where those most affected by AIDS mostly lived.”⁷²²

Psychologist and epidemiologist John Newmeyer, who began working with AIDS in late 1982 at San Francisco’s Haight-Ashbury Free Clinic, offered a sobering assessment of the impact of AIDS on gay people and on America. Because AIDS mostly affected young people, he said, the years of potential life lost far surpassed those lost to the nation’s other leading causes of death, which mostly afflict older people. He explained that if a man dies at thirty-five who would otherwise live to seventy, thirty-five years of life are lost. Said Newmeyer, “When the cancer people say we have four hundred thousand people dying of cancer a year and AIDS kills only eight thousand a year, that doesn’t account for years lost. Added up over all the gay men who’ve lost their lives to AIDS, the number is staggering.”⁷²³

Andrew Sullivan, the openly gay and HIV-positive *Atlantic* blogger, said that for gay people, “Death is less an event than an environment.”⁷²⁴ The toll of living in what seemed to many gay men in the nation’s cities like a battlefield on which they witnessed the protracted and brutal deaths of so many of their young comrades has scarred them, us, for life. One of the first articles ever to assess the psychological impact of AIDS upon

⁷²². David Firestone, “Life Span Dips for Men Born in New York: AIDS is the Main Reason for Decline, Report Says,” *New York Times* (27 April 1996), 25.

⁷²³. John Newmeyer, interview with author, San Francisco, 31 January 1995.

⁷²⁴. Andrew Sullivan, “Gay Life, Gay Death,” *New Republic* (17 December 1990), 19–25.

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gay men said that it was “omnipresent and profound.”⁷²⁵ That was hundreds of thousands of deaths ago.

While preparing a sermon to commemorate the bombing of Hiroshima, Chris Glaser was struck by the parallels between the ways that city’s survivors coped with their horrific devastation and the gay community’s coping with AIDS. Acknowledging the obvious differences between the two disasters, Glaser also pointed out the truly striking similarities. Survivors of the atomic blast felt as though “the whole world is dying,” noted Glaser. “As gay men, our encounter with death from AIDS seems endless,” he said. He likened the lingering threat of invisible contamination from radiation to the long incubation period of HIV in the body, “which may strike at any time.”

Describing the way Hiroshima’s survivors would continue to associate any kind of physical ailment with the atomic blast, Glaser said, “The similarity to the experience of gay males is stunning. If we feel fatigued, experience any ailment from a cold or flu to an infection, our thoughts immediately turn to AIDS and death.” Finally, he observed that the atomic blast survivors were stigmatized as “a tainted group” because of a lifelong identification with death and dying. Even worse, they questioned their own right to live “because of an unconscious perception of balance which supposes one’s survival has been made possible by others’ deaths.”⁷²⁶

⁷²⁵. Stephen F. Morin, Kenneth A. Charles, Alan K. Malyon, “The Psychological Impact of AIDS on Gay Men,” *American Psychologist* 39 (November 1984): 1288–93.

⁷²⁶. Chris Glaser, “AIDS and A-Bomb Disease: Facing a Special Death,” *Christianity & Crisis* (28 December 1987).

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This “survivor guilt” has been widespread among gay men old enough to have lived through the dark years of AIDS, particularly those who are not infected with HIV. There was a feeling that one somehow didn’t deserve to live when so many good and wonderful others “who did the same things I did” have not survived. To ameliorate this guilt, many gay men got involved with gay or AIDS organizations.⁷²⁷ Many others downplayed their feelings, devalued the importance of their personal losses, and tried to carry on as though they really didn’t feel that their heart had been wrenched out of their chest and an aching wound left in its place.

What’s more, there was something of a conspiracy of silence among many gay people who experienced the most loss, a hesitation to speak about their losses, even among themselves, because they didn’t want to remind those living with HIV—in the years before antiretroviral therapy made it possible to live with HIV, rather than die from AIDS—that, barring a stunning breakthrough in medical research, they too were likely to join those who are mourned. Walt Odets wrote in *In the Shadow of the Epidemic*, “[I]f a man feels guilt or unworthiness for having had the good fortune to survive when another has not or will not, he will find it very difficult to recognize his own distress and almost impossible to talk about it.”⁷²⁸

Before the wider use of the HIV antibody test in the late eighties and nineties, all gay men were told by AIDS educators to presume they were infected. But the ability to know whether

⁷²⁷. Fred Boykin, “The AIDS Crisis and Gay Male Survivor Guilt,” *Smith College Studies in Social Work* (June 1991): 256.

⁷²⁸. Walt Odets, *In the Shadow of the Epidemic: Being HIV-Negative in the Age of AIDS* (Durham, NC: Duke University Press, 1995), 42.

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or not one is infected had profound implications for the ways that gay men experienced “survival” and bereavement, as demonstrated in a study by Columbia University researchers, the late John Martin and Laura Dean.⁷²⁹ They found that the psychological impact of AIDS-related losses had already diminished among gay men who survived the first decade of the AIDS epidemic. They pointed out, however, that this might have been due to the fact that gay men were becoming habituated to the experience of AIDS-related loss. That is to say the deaths of young men became so commonplace as to make this inversion of the natural order seem “normal.”

Even today, men who are infected experience great psychological distress. Those of us who are survivors of the dark years recall too well what untreated HIV looks like, the appalling illness and death we witnessed in our friends and loved ones. It isn’t easy to put such painful images out of one’s mind when it is clear that access and adherence to very toxic, very expensive medications are all that keep us on *this* side of the looking glass of AIDS. We know that, despite treatment advances, there is still a real chance we could experience a similar fate. Men who are not infected, especially in the earlier years, were often distressed as well; they might have had depression and traumatic stress, used sedatives, and even thought about suicide. But their distress was likely to be less acute because they didn’t see their friend or lover’s death as a portent of their own.

Some HIV-positive activists protested that HIV-negative men shouldn’t complain about the psychological burden they bear.

⁷²⁹. John L. Martin and Laura Dean, “Effects of AIDS-Related Bereavement and HIV-Related Illness on Psychological Distress Among Gay Men: A 7-year Longitudinal Study, 1985–91,” *Journal of Consulting and Clinical Psychology* 61 (1993): 94–103.

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No matter how heavy it may be, they argued, it wasn't at all the same as the utterly shattering impact of being infected with a deadly pathogen. Atlanta physician Stosh Ostrow spoke frankly about living with HIV and about his belief that those who are not infected cannot fully understand what it's like. "Those of us who live in the shadow of the epidemic have a whole different perspective on life," Ostrow told me in 1995. "HIV-negative gay men don't have a clue what it's like, nor am I capable of explaining what it's like to live with HIV." Like many gay men with HIV, Ostrow said that living with the virus "made me become conscious." He spoke of "living each day as a gift," adding that for most people, "Life, longevity, is an illusion."⁷³⁰

No one who doesn't live with HIV infection can fully grasp the often powerful uncertainty and anxiety of living with a medically managed, yet still deadly, virus in one's body, as well as the stigma that remains powerful even among too many gay men. But the line dividing our experiences of loss and sorrow and those of gay men who are not infected is not as sharply drawn as some activists' hostile denunciations of what they called "viral apartheid" would make it. As the late Eric Rofes put it, "We love to talk about 'viral apartheid,' but in daily life positive and negative are involved with one another."⁷³¹ Still, Rofes, like other uninfected men with whom I've spoken, was offended by the efforts of some to challenge the emotional impact of the epidemic on the lives of gay men who happened not to be infected with HIV. "What galls me about this," he said, "what I find remarkable about this, is no one talked to survivors of Nazi death camps and said, 'Well, you're a survivor, you have no problems, what are you complaining about.' No one talked to

⁷³⁰. Stosh Ostrow, MD, telephone interview with author, 23 September 1995.

⁷³¹. Eric Rofes, telephone interview with author, 7 July 1995.

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survivors of the dropping of the bomb on Hiroshima and said, 'You're one of the ones who lived, not one of the hundred thousand who died, what are you complaining about.'⁷³²

Speaking as one who experienced the first twenty-five years of the AIDS plague as an HIV-negative gay man before testing positive, I would say there is a wide chasm between being a survivor of loss and knowing that the murderer of your loved ones is lodged within your own body. One can be reasonably confident his eventual death will not be like his friends'; the other can't be entirely sure. He may even suffer some secondhand stigma from being close to a person with HIV. But the other lives with visceral fear for his very life and with the firsthand stigma imposed on him for simply having had the misfortune to become the unwelcoming host of a microbe fraught with what many insist is "meaning."

Many men who lived through the dark years remark that they feel much older than their years. In a 1989 essay called "Friends Gone with the Wind," Arnie Kantrowitz observed, "We are aging before our time. When we meet old friends in the street, we remember to be glad they are still with us. Our conversation sounds like my grandfather's did when he was in his eighties."⁷³³ One of the most arresting illustrations of this sense of premature aging and bereavement is in a poem by Michael Lassell called "Pietà":

⁷³². Rofes interview.

⁷³³. Arnie Kantrowitz, "Friends Gone With the Wind." In John Preston, ed., *Personal Dispatches: Writers Confront AIDS* (New York: St. Martin's Press, 1989), 21.

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A man who is ill
visits his mother
in her nursing home.

You don't look well, she says.
Neither do you, he says.

My friends are all dying, she says.
My friends are dying, too.

I'm afraid that when I die
there will be no one left to
say prayers at my grave, she says.
It's my fear, too, he replies.

And they sit and weep,
each dropping tears onto
the hands of the other,
waiting for the after
that follows hard
the heels of time.⁷³⁴

For gay people in 1990s America, imminent loss was to our time "what industrial optimism was to the times of our parents and grandparents," as *Angels in America* author Tony Kushner put it.⁷³⁵

⁷³⁴. Michael Lassell, *Decade Dance* (Boston: Alyson Publications, 1990), 69.

⁷³⁵. Tony Kushner, "The Angels in America Author on Beauty and Remembrance," *Architectural Digest* (November 1995), 28.

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Still, many were afraid to really feel and express their losses. As Eric Rofes put it, “We fear that if we open up, we’ll never stop crying.”⁷³⁶ A gay man who shares his stories with others, who actually describes what he witnessed and felt, risks admitting his sense of impotence in the face of an overwhelming disaster like AIDS. He risks having to let down the guard with which he’s had to protect his emotions simply to survive. Fortunately, many gay men realize they must take these risks if they are truly going to survive. Again, Rofes, “By underplaying or denying the full range of impact of the epidemic and its power to transfigure emotions, memories, and psyches, the souls of gay men are kept locked in a perpetual winter.”⁷³⁷

If gay people downplayed their losses because they were so overpowering, nongay people too often downplayed the gay community’s losses because they refused to recognize the humanity they share with homosexual people. Even so, homophobia alone didn’t account for the disdain and neglect shown to gay people with AIDS and their survivors; what did account for it is a fear of death that pervades American culture. To acknowledge that so many have died at such youthful ages of a disease that science to now has been unable to cure carries an expensive cost: you must surrender your denial that you will eventually die. As John Snow, an Episcopalian priest and professor of pastoral theology at the Episcopal Divinity School, put it, “Is it any wonder that AIDS has brought such a mixed and confused and at times almost insane response from our society? A society that thought it might have death on the run has discovered or uncovered what we suspected all along and tried

⁷³⁶. Rofes, *Reviving the Tribe*, 79.

⁷³⁷. *Ibid.*, 238.

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so hard to deny. We have discovered that human beings are irretrievably mortal.”⁷³⁸

Many heterosexuals have long associated homosexuality with death, at least partly because the traditional absence of children in many gay people’s lives affronted the belief that one achieves a kind of vicarious immortality through children.⁷³⁹ Jeff Nunokawa writes that even before the AIDS epidemic American culture regarded homosexuals as “marked men,” doomed because of their homosexuality to early death. Despite worldwide evidence to the contrary, he notes that in the eyes of many, gay men with AIDS are “not only people with AIDS but *the* people with AIDS.” The connection between AIDS and gay men, he adds, “encourages our culture’s sometimes distaste for, and anxiety about, homosexuality.”⁷⁴⁰

Ben Schatz eloquently described the tenuous place of gay men in an American society bent on denying their humanity and ignoring AIDS. “I sometimes feel like gay men are dangling by their fingers from the edges of a roof,” he said, “and every minute or so you can look over at the man next to you just in time to see him let go and drop. But on top of the roof, the rest of the country is having a cocktail party—and except for those people who are walking around stepping on our fingers, they’re

⁷³⁸. John Snow, *Mortal Fear: Meditations on Death and AIDS* (Cambridge, Mass.: Cowley Publications, 1987), 14.

⁷³⁹. James B. Nelson, *Embodiment: An Approach to Sexuality and Christian Theology* (Minneapolis: Augsburg Publishing House, 1978), 204.

⁷⁴⁰. Jeff Nunokawa, “‘All the Sad Young Men’: AIDS and the Work of Mourning,” *Yale Journal of Criticism* (Spring 1991): 1–12.

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not even aware we're hanging there. Yet man after man lets go and falls, and you're dangling there and thinking, 'Can I really hang on? How long can I hang on? This seems impossible.' And man after man loses his grip and falls to his death, and up above you hear ice tinkling in the glasses, but the pile of bodies down below is just getting higher and higher."⁷⁴¹

Nongay America relegated the massive deaths of gay men in the AIDS epidemic to the sidelines of its collective consciousness by discounting the lives of those who, in this country, still constitute the largest share of the plague's victims. For many, AIDS offered a return to the debunked view that homosexuality is a "disease," and that homosexuals, somehow other than full human beings, actually have their "own" diseases.

In a powerful collection of photographs of 302 people who had died during one year of the AIDS epidemic—a fraction of the estimated 4,000 who actually died during that time—*Newsweek* in August 1987 noted, "Some commentators have found a degree of comfort in the statistics, as if AIDS had been satisfactorily contained in an alien population. It has not been; it has struck to the quick of American life." The magazine continued, "Each face in the album stands for a life cut short too soon; each represents a death in the American family."⁷⁴² We are then presented with twelve pages of snapshots. The overwhelming majority of the photos are of young men, and we are led to assume, through veiled references to their personality or work, that they are gay. Below the photos of the fifteen women and two children pictured in the collection—one of them for every eighteen men—are explanations of how they became in-

⁷⁴¹. Odets, *In the Shadow of the Epidemic*, 74.

⁷⁴². "The Face of AIDS: One Year in the Epidemic," *Newsweek* (10 August 1987), 22–37.

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fects with HIV. We have little choice but to conclude that the men pictured without such explanations contracted HIV merely by being gay, that AIDS is a “normal” end of a gay life.

Even in its admirable attempt to show “the face of AIDS,” *Newsweek* perpetuated the myths that comfort heterosexual Americans: that gay people are somehow different from “normal” human beings, and that AIDS is a “gay” disease that afflicts only sexual deviants and drug addicts (and their unfortunate offspring). But even nongay people who contract HIV aren’t allowed to be really “innocent”: the caption beneath one woman’s photo actually says, “She was a drug addict.” This is presumably *Newsweek*’s version of a sympathetic epitaph. As Cindy Patton has put it, “[T]he huge stigma of contracting HIV continued to make every individual person living with the virus suspect of having ‘done something wrong.’”⁷⁴³

The American family, as *Newsweek* represented it, seems clearly to have its favorite members as well as those whose “private” behaviors and sorrows must be kept out of sight (and out of mind) lest they reveal the family not to be nearly as loving as it prefers to see itself. By dying so young and in such vast numbers and of such a horrific, incurable disease, gay men audaciously pulled the mask off the mysterious guest at

⁷⁴³. Cindy Patton, *Fatal Advice: How Safe-Sex Education Went Wrong* (Durham, NC: Duke University Press, 1996), 64.

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the nation's party, revealing that in fact Death has been among us even as we believed ourselves safe.⁷⁴⁴

⁷⁴⁴. "And now was acknowledged the presence of the Red Death. He had come like a thief in the night. And one by one dropped the revelers in the blood-bedewed halls of their revel, and died each in the despairing posture of his fall." Edgar Allen Poe's "Masque of the Red Death" is eerily relevant to the denial with which America has handled the AIDS epidemic. See *Tales of Mystery and Imagination By Edgar Allen Poe* (New York: Weathervane Books, 1935).

THIRTY-THREE

John had passed in and out of lucidity since being admitted to George Washington University hospital the day before. Pain shook his frail body one moment, morphine appeased it the next. His mother, father, and brother were down from Baltimore and would stay to the end—which would come in a matter of hours, the nurse said. Manny waited with John. For three years he knew this moment would come. Now this was it. Goodbye. Nine years of togetherness was ending in this hospital room. John, his thirty-nine-year-old lover, was dying of AIDS.

John was never a “patient,” Manny told me. He demanded nothing. In fact, Manny worried that one morning he would wake up to find that John had died in bed next to him, not wanting to disturb his sleep. But on John’s last morning—the morning after Gay Pride Day—he called Manny’s name over and over again. Manny had left the hospital at two, seeking much-needed rest. “Manny will be here soon,” John’s mother assured him. Manny returned at seven. The nurse gave John another shot of morphine to soothe the now-incessant pain. They called in a priest from nearby St. Stephen Martyr. John’s mother sat at the foot of her son’s bed, quietly saying her rosary. Manny held John’s hand.

A final gasp and he was gone. It was over now for John. And just beginning for Manny. Manny was single again. And not just a single man, but a man whose lover had died of AIDS—which, even in the frightened gay community, stigmatized him by association. Manny would still attend Dignity, the weekly gay Catholic masses where he and John had met and sung in the folk group. The next Sunday, Dignity would offer a memorial

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service for John, the one John had planned for himself in such detail. John's parents would come. His friends would turn out in number to pay their last respects to the former seminarian, the man who had led them as Dignity's president, who in loyalty to his church had taken a lesser job with the National Catholic Conference rather than leave altogether when they learned he was gay and wanted him out. The service was simple, a folk mass. John's favorite homilist spoke, his favorite songs were sung. "That made it easier," said Manny. "It wrapped up the whole week."

Manny hadn't cried in the three months between the time of the memorial service and our interview, although he said there were teary moments. Mostly he wondered what grieving is. Is it being sad? Crying? Feeling helpless? Is it anger? "I've read a book on coping," he said. "But I don't even know what I'm supposed to be coping with." Back home in the Philippines, Manny said there are traditions surrounding a spouse's death. There is the novena, the nine days of prayer. On the ninth day there is a big party to celebrate the dead person's passing. Then there's a whole year of formal mourning to be observed. But Manny wasn't sure whether this applied to his mourning John's passing. After all, John hadn't *really* been his spouse, had he?⁷⁴⁵

When I wrote about Manny and John, in 1986, there was precious little information in the psychological literature about the bereavement of gay men. Laura Dean, director at the time of the AIDS Research Unit of Columbia University's School of Public Health, recalled that one of the first papers she and her research partner John Martin (Martin himself died of AIDS in 1992) wrote on bereaved gay men was rejected by a journal.

⁷⁴⁵. John-Manuel Andriote, "The Survivors: How Do You Grieve the Loss of a Forbidden Love?" *Washington City Paper* (19–25 September 1986), 1.

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She told me, “One of the reviewers said, ‘This is ridiculous, why would you expect a gay man to grieve over a lover?’”⁷⁴⁶

Before AIDS, though, even gay men didn’t think about their partners’ deaths. Nor, for that matter, did they think much about death in general. Like their fellow Americans, gay men simply didn’t want to think of death as anything more than a vague abstraction, something that would take place in a far-off old age—at a time that, for young gay men, was like a netherworld somewhere beyond their “real” lives. In 1981, the first year of the epidemic, psychiatrist and *The Joy of Gay Sex* coauthor Charles Silverstein published *Man to Man*, the first book devoted to the subject of gay male love-relationships. He noted how gay men in the pre-AIDS years were at least as resistant to confronting their mortality, as were their nongay counterparts. “Gay men don’t die,” he wrote. “The word ‘death’ never appears in gay newspapers or magazines unless it is related to the assassination of a civil rights leader. Fashionable bodies, lately adorned with beards and a narrow piece of studded leather around the wrist, fill the slick magazines that fuel our ever-present fantasies of seduction and sex. No room for death there.”⁷⁴⁷

Although widespread death became a harsh fact of life for gay men in the eighties and nineties, death at a young age is still considered an “off-time event,” because one ordinarily expects to confront it only in old age. But AIDS altered many of our expectations as it became the leading cause of death

⁷⁴⁶. Laura Dean, interview with author, New York City, 29 April 1995.

⁷⁴⁷. Charles Silverstein, M.D., *Man to Man: Gay Couples in America* (New York: William Morrow, 1981), 265.

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among twenty-five to forty-four-year old Americans.⁷⁴⁸ The AIDS epidemic reversed the natural order of life as the old buried the young and the young buried one another. Still another bizarre twist with AIDS was that a surviving partner himself was often infected with HIV, something that rarely happens with other life-threatening diseases.

In the quarter-century since I wrote about Manny's uncertainty of how to mourn his lover's death, somewhat more attention has been paid to the bereavement of gay men who have lost partners to AIDS. Unfortunately, Manny could not benefit from whatever comfort the new information might offer because within five years after our interview he, and virtually every other man I interviewed for "The Survivors," was dead from AIDS.

Despite the increased interest of researchers in the bereavement of surviving partners, the greatest single issue with which gay men had to grapple is the same today as it has always been: the lack of recognition of their love relationship with the dead man. The efforts to gain such recognition are the very cornerstones of the gay rights movement, said veteran activist Ginny Apuzzo. "We still fight for the right to love," she told me. "The one thing that we are told we can't do is the thing that makes us most human—that is, to love. You can't grieve what you didn't love. You can't be in this much pain and not have had love. How can you be a widower and not have had a spouse? How can you bury the single most important person to you, with whom you've lived for x-number of years, and not have had a relationship? What the hell was it?"⁷⁴⁹

⁷⁴⁸. Philip J. Hilts, "AIDS Deaths Continue to Rise in 25–44 Age Group, US Says," *New York Times* (16 February 1996), A22.

⁷⁴⁹. Virginia Apuzzo, telephone interview with author, 8 August 1995.

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The absence of society's approval—and especially the overwhelming disapproval—of gay relationships led some gay men to disavow their partners at the moment of their greatest need. Telling themselves “it wasn't really a marriage anyway,” some abandoned the man they professed to love because they were unable to confront the horrors of an AIDS death; or because they didn't have the fortitude to confront the internalized homophobia they turned against themselves and their relationships. Gerald Soucy, then a mental health consultant at Chicago's Howard Brown Memorial Clinic, told me in 1986, “In order to avoid dealing with grieving, the hole, the emptiness left by death, you minimize to yourself the amount of intimacy that was in the relationship. You try to minimize the gap left in your life.”⁷⁵⁰ You convince yourself that even your own feelings of love are suspect and somehow inferior to those of a heterosexual spouse, so it's okay to leave—after all, you're not legally bound to stay.

Tony Kushner captured this self-hatred and abandonment in the character of Louis, who deserts his boyfriend Prior Walter, the central character in *Angels in America*, who has AIDS:

LOUIS: Rabbi, what does the Holy Writ say about someone who abandons someone he loves at a time of great need?

RABBI ISIDOR CHEMELWITZ: Why would a person do such a thing?

LOUIS: Because he has to ... maybe that person can't, um, incorporate sickness into his sense of how things are supposed

⁷⁵⁰. John-Manuel Andriote, “Coping with Grief in the Time of AIDS,” *Windy City Times* (27 March 1986), 6.

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to go. Maybe vomit ... and sores and disease ... really frighten him, maybe ... he isn't so good with death.

RABBI ISIDOR CHEMELWITZ: The Holy Scriptures have nothing to say about such a person.

LOUIS: Rabbi, I'm afraid of the crimes I may commit.

Louis eventually attempts, unsuccessfully, to return to Prior, but only after complaining about being tormented by his guilt as symbolized in mental images of "Biblical things, Mark of Cain, Judas Iscariot and his silver and his noose, people who...in betraying what they love betray what's truest in themselves."⁷⁵¹

Most gay men whose partners had AIDS did not leave them the way Louis left Prior. They toughed it out as best they could in the face of a hideous disease and the hatred of others who couldn't imagine "gay grief" because they couldn't imagine the love of two men for one another. Remarking on the support she observed gay men giving their partners and friends even early in the epidemic before we knew how AIDS was caused, Elisabeth Kübler-Ross, the world's best-known authority on death and dying, said, "They were willing to hold those young dying men in their arms so they would not feel unloved and deserted at the end of their lives. In those days they were unaware that once could not catch the disease by sheer proximity, yet they

⁷⁵¹. Tony Kushner, *Angels in America: A Gay Fantasia on National Themes, Part One: Millennium Approaches* (New York: Theatre Communications Group, 1992), 25, 99.

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were still willing to risk their young lives to ease their friends' suffering."⁷⁵²

But even survivors who stuck around had to make their way through the emotional minefield of bereavement, largely unguided, because there are no established norms for mourning the death of a gay partner: A surviving lover isn't called a widow or widower. Rarely do financial benefits—a widow's pension, for example—accrue to him upon his partner's death. Typically he can't take time off from work. If he does, and if he wasn't "out" about being gay with his coworkers, they'll wonder about the intensity of his feeling for someone who was "just a friend," or "just a roommate."⁷⁵³ This lack of recognition of the relationship, the loss, or the griever has been described as "disenfranchised grief."⁷⁵⁴

The surviving partner's disenfranchisement was often felt most acutely with respect to the family of the dead man. One of the first studies of surviving lovers noted that although some families accepted the lover, many did not. There were arguments over arrangements, financial settlements, and disposal of possessions. "These problems are, of course, not unique to the AIDS situation," noted the authors. Nor did they originate in the 1980s. In fact, gay male partners were being pushed aside

⁷⁵². Elisabeth Kübler-Ross, *AIDS: The Ultimate Challenge* (New York: Macmillan, 1987), 11.

⁷⁵³. Andriote, "The Survivors."

⁷⁵⁴. Judith Pollatsek, "Grief, Multiple Loss, and Burnout: Care for the Caregiver." Speech presented at the National HIV Frontline Forum, 1994, and published in *Multimedia Self-Study Kit for Professionals Who Counsel People Living with HIV* (New York: NCM Publishers, 1994).

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by biological families long before the AIDS epidemic. In the seventies, Howard Brown observed that “Relegated to the status of mere friend, the surviving partner must watch helplessly as members of his lover’s family move in and establish their claim as next of kin, as they make funeral arrangements their own way, possibly shipping the body out of town.”⁷⁵⁵

In *My Own Country*, Abraham Verghese describes his years as a physician who became, of necessity, the AIDS doctor in rural Johnson City, Tennessee. There he tended to HIV-infected gay men who had mostly grown up in the area and whose experience of gay life consisted largely of dancing at the one local gay bar, and furtive sexual encounters with one another and with the interstate truckers who passed through on their way north or south.

Verghese’s own experience as a foreign-born, albeit heterosexual, doctor meant he knew what it was like to be cast in the role of the “outsider.” He poignantly captures the shattering effect of a gay man’s being pushed aside by his dying lover’s biological family when decisions are made as to whether or not to put the man with AIDS on artificial life support, something the man himself was adamantly against:

The oldest brother spoke again. His tone was matter-of-fact and determined:

“We are his family. We are legally responsible for him. We want you to do everything for him.”

We are his family. I watch Bobby’s face crumble as he suddenly became a mere observer with no legal right to

⁷⁵⁵. Howard Brown, MD, *Familiar Faces, Hidden Lives: The Story of Homosexual Men in America Today* (New York: Harcourt Brace Jovanovich, 1976), 140–41.

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determine the fate of the man he had loved since he was seven years old. He was finally, despite the years that had passed and whatever acceptance he and Ed found together, an outsider.⁷⁵⁶

Of course there were families that respected their adult children's relationships, though their support may have been largely unspoken. Jim Halloran, a registered nurse in Houston who had drawn upon his training in oncology nursing to care for people with AIDS, described the trying time he had in dealing with a lover who didn't want his family to know he had AIDS—even though they accepted the two men's relationship. The family was present when Halloran's John died. The word AIDS was never used. Legally, Halloran held power of attorney, though, as he pointed out, "a piece of paper doesn't matter to family dynamics."

After the funeral, Halloran and John's sister were standing outside on the porch. "I was talking with Carmen, John's oldest sister, the matriarch of the family aside from Mama," he recalled. "I said, 'Carmen, there's something I want to tell you. In a week or two I'll send you all death certificates because you might need them for something. And on it, it's going to say that John died of AIDS.'"

Halloran expected a blowup. But Carmen just nodded, said it wasn't a problem, and added that she probably would have gone about things the same way. Said Halloran, "Talk about a lesson. Here we are with our doctrine and dogma of here's how

⁷⁵⁶. Abraham Verghese, MD, *My Own Country: A Doctor's Story* (New York: Simon & Schuster, 1994), 223.

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you do things—when the basic, simple truth is that within a family, family members know best how that family operates.”⁷⁵⁷

In the late eighties, Randy Shilts reported that while some families abandoned their “leper” children, many others experienced a renewal of family ties after what may have been years of estrangement. “For many families,” wrote Shilts, “news of a Kaposi’s sarcoma or *pneumocystis* diagnosis rendered a dual diagnosis, informing the parent both of the child’s disease and sexual orientation.”⁷⁵⁸

Families that had struggled to understand and accept their son’s sexual orientation now were confronted by a disease that many in the country believed was either a result of or punishment for homosexuality. For parents of gay men, the question “What is the risk for AIDS?” became a terrifying addition to the usual concerns about having a gay child, such as “What will our neighbors say?” and “Where did we go wrong?” An April 1987 survey of 402 parents who were involved with the group Parents and Friends of Lesbians and Gays (P-FLAG) found that AIDS had reopened old wounds even for parents who had already come to terms with their child’s homosexuality.⁷⁵⁹

Some parents reacted with hatred and anger, rejecting their gay sons at their moment of direst need because the sons were gay and had contracted the so-called “gay disease.” John Paul Barnich recounted a particularly loathsome incident in Houston.

⁷⁵⁷. James Halloran, telephone interview with author, 10 October 1995.

⁷⁵⁸. Shilts, *And the Band Played On*, 356.

⁷⁵⁹. Bryan Robinson, Patsy Skeen, Lynda Walters, “The AIDS Epidemic Hits Home,” *Psychology Today* (April 1987), 48–52.

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“We had a little munchkin from L.A.,” he said. “Joey, a street hustler. He had lymphoma of the brain.” Given the gravity of Joey’s condition, Barnich, then on the board of AIDS Foundation Houston, called Joey’s father in Los Angeles. The father said he had no interest in seeing his son. When Barnich offered to raise money to pay the man’s airfare, he still resisted. Barnich recalled asking, “What would you like us to do with the body?” To which Joey’s father replied, “Put the little son-of-a-bitch in a Hefty trash bag and leave him out by the curb.”⁷⁶⁰

People like Joey’s father notwithstanding, many other parents responded with love, as outraged as their gay sons by the cowardice and neglect of the federal government and their fellow Americans in dealing with the epidemic. Suzanne Benzer is the consummate New York woman—slim and attractive, outgoing, energetic, and determined. Benzer was a board member of Mother’s Voices, a group founded in 1991 by five mothers who had lost a child to AIDS. The group’s main purpose is to channel the mother’s and other family members’ grief into a movement aimed at changing public attitudes and policies. As we sat in the Manhattan office of Mothers’ Voices, Benzer described what it had been like for her to see her twenty-eight-year-old son Bobby living with HIV.

“About four years ago,” she told me in 1995, “we suspected that my son was gay. He was involved with a boy, and the boy got AIDS.” Benzer immediately called GMHC because she didn’t know much about AIDS. “I raised my boys myself, so I’m pretty tough,” she said. “But I was out of control. I couldn’t make this better for him, and I still can’t—either emotionally or physically, I can’t. I can be there, but I’m completely powerless to make my child better.” Benzer started going to a support

⁷⁶⁰. John Paul Barnich, telephone interview with author, 1 October 1995.

VICTORY DEFERRED

group sponsored by the PWA Coalition. Downstairs were all the mothers who had children with AIDS; upstairs were mothers whose children had died. She said, "It was metaphoric because you went up the stairs when your child died."

Like other mothers and family members involved with Mothers' Voices, Benzer's grief over her son's condition turned into anger as she learned more about AIDS and about the government's stumbling efforts to address the epidemic. She joined ACT UP, "doing actions" such as sitting in the middle of the Brooklyn Bridge to protest, which helped her get through some of the anger and rage. "I never thought I'd see myself sitting in the middle of the Brooklyn Bridge," said Benzer. "I was an upper-middle-class lady. This was not what I thought life would hold for me. But my son..." She doesn't complete the sentence.⁷⁶¹

Other mothers joined ACT UP for the same reasons Benzer described. They called themselves "ACT UP in sheep's clothing" because, as mothers, they were able to appeal to heterosexual politicians on the basis of their shared "family values." ACT UP and Mothers' Voices board member Eileen Mitzman, whose daughter Marni died of AIDS at age twenty-six in 1991, typically set a picture of her daughter on legislators' desks, near their own family photos. "That's the only way to get them," she said. For years, she pointed out, they didn't identify with anyone who had AIDS. It wasn't their disease, so they did nothing. "Now," said Mitzman, "we show them pictures of children who look like their children, and they gulp."⁷⁶²

⁷⁶¹. Suzanne Benzer, interview with author, New York City, 26 April 1995.

⁷⁶². Georgia Dullea, "AIDS Mothers' Undying Hope," *New York Times* (20 April 1994), C1.

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Because many gay people live far from their families, often in the nation's large cities where they feel more comfortable living their lives openly, they often regard their circles of close friends as the kind of family that Armistead Maupin said was common in San Francisco in the seventies. These gay family networks have been invaluable for gay men with HIV and AIDS, providing both practical and emotional care and support. Traditionally, parents, spouses, and adult daughters have been the informal caregivers of people who have an incurable disease.⁷⁶³ But in these "chosen families," gay men have broken the mold of the traditional roles that men are expected to play in caring for ill family members. For the first time ever, American men actually became primary caregivers.

When she was supervising buddies and crisis intervention workers at GMHC, Sandi Feinblum said she heard many gay men say, "I never thought I was capable of doing this." One man in particular stood out in her memory, a man in his forties who became a crisis worker. Feinblum recalled, "When he would tell his friends and family—he was fairly well-to-do, kind of a fancy queen—they all laughed and said, 'You? We'll give you four days!'" She added, "It was so striking to him that people thought he was superficial and that nobody took him seriously. He realized that this was a big test to himself of who he was." Even gay men, often accustomed to being more comfortable than heterosexual men with the "feminine" aspects of their personalities, had to learn to be comfortable in caregiving roles traditionally assigned to women. Typically women didn't struggle over whether they were comfortable in such roles because,

⁷⁶³. Susan Folkman, Margaret A. Chesney, Anne Christopher-Richards, "Stress and Coping in Caregiving Partners of Men With AIDS," *Psychiatric Clinics of North America* (March 1994), 35–53.

VICTORY DEFERRED

as Feinblum put it, “they’ve accepted that they’re going to be helpers.”⁷⁶⁴

The losses of professional AIDS helpers—particularly doctors, nurses, and psychotherapists—have often been overlooked. Those who aren’t in the health care professions assume that the severe illness and death these people confront in their patients are simply a kind of occupational hazard, easily handled by trained professionals. But even trained health care professionals weren’t prepared for the ghastly diseases and deaths of young people they confronted repeatedly in the AIDS epidemic. Like surviving lovers of gay men with AIDS, the late Washington, DC, bereavement expert and therapist Judy Pollatsek said that the grief of professional caregivers was “disenfranchised” because it was so typically unrecognized. If they were gay themselves, it was magnified by the fact that even in their personal lives they were likely to have dealt with AIDS in friends, the community—or themselves. And it was profound: shell-shocked doctors, nurses, social workers, therapists, and others were forced to confront death after relentless death. As Pollatsek put it, “We have not been trained to lose so many battles with so many people who are just like us.”⁷⁶⁵

Even health care professionals sometimes had to step back from their work with AIDS patients because the stress and grief overwhelmed them. Washington, DC, psychiatrist Jeff Akman said he had to limit the number of people with AIDS he saw in psychotherapy. “There’s a certain number I can tolerate without destroying my own psychological health or my relationship or

⁷⁶⁴. Sandi Feinblum, interview with author, New York City, 26 April 1995.

⁷⁶⁵. Pollatsek, “Grief, Multiple Loss, and Burnout: Care for the Caregiver.”

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ability to work,” he told me. Akman said he was able to keep working with AIDS patients, as he had been doing since AIDS first appeared in Washington, by focusing on the rewards of his work. He explained, “You have to think about the unbelievable gallantry of people who face this day in and day out, who deal with this awful illness and suffering and pain and death. I think in many ways it’s the gallantry that sustains me, that makes practicing as a physician who mostly sees AIDS patients and people with HIV very rewarding.”⁷⁶⁶

For a person with HIV, grief begins at diagnosis. Like people with other life-threatening illnesses, such as cancer, people with HIV go through a bereavement in which they mourn for themselves. Besides mourning very real losses—the loss of assumed good health, possibly of an attractive appearance because of medication side effects, or a job and financial independence—people with HIV experience a kind of “anticipatory grief” for our own potential death.⁷⁶⁷ For gay men with HIV who never confronted their internalized homophobia, diagnosis could unleash feelings of unacceptability. The disease could reactivate feelings of self-loathing even in men who had come to terms with being gay years earlier. This often had profoundly negative effects on gay people with HIV. If they accepted and internalized the stigma that American society attached to HIV, they might feel such extreme shame that they felt unentitled to

⁷⁶⁶. Jeffrey Akman, M.D., interview with author, Washington, D.C., 17 March 1995.

⁷⁶⁷. Fawzy I. Fawzy, Nancy W. Fawzy, Robert O. Pasnau, “Bereavement in AIDS,” *Psychiatric Medicine* 9 (1991): 469–82; Caitlin Conor Ryan, “The Social and Clinical Challenges of AIDS,” *Smith College Studies in Social Work* 59 (November 1988): 3–20.

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live, in which case they might not seek or adhere to their medical treatment.⁷⁶⁸

Karl Goodkin, a psychiatrist at the University of Miami at the time of our 1995 interview, became interested in exploring the relationship between the bereavement of gay men with HIV infection and AIDS and the functioning of their immune systems, after observing that men who had a hard time dealing with their losses seemed to become clinically ill faster. There is a strong belief in the emerging field of psychoneuroimmunology that a relationship exists between an individual's psychological health and the functioning of his immune system. Goodkin, a proponent of this view, described what he called "active" and "passive" coping, personal styles of dealing with loss that are respectively either hopeful or hopeless. Active copers are realistic about their health and the impact of the AIDS epidemic on their lives and community. Rather than feeling helpless, though, these people look at their HIV infection as an impetus to take control of their lives, to become politically involved, or to work with local AIDS organizations. Goodkin was intrigued by the fact that active copers seemed to do better with their disease and to live longer than passive copers. They had higher CD4 counts and positive changes in natural killer cell function, another immune measure believed to be important in later HIV disease unmanaged by antiretroviral therapy, when these cells take over from the vanquished CD4 cells in defending the individual against viral illnesses and cancers.

⁷⁶⁸. Gil Tunnell, "Special Issues in Group Psychotherapy for Gay Men with AIDS." In Steven A. Cadwell, Robert A. Burnham, Jr., and Marshall Forstein, eds., *Therapists on the Front Line: Psychotherapy with Gay Men in the Age of AIDS* (Washington, DC: American Psychiatric Press, 1994), 239–40.

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Goodkin felt that loss was perhaps one of the most stressful events that people with HIV—particularly gay men—had to cope with on a chronic basis, both individually and in the community. In fact, Goodkin found a strong correlation between the loss of a significant other in the prior six months and decreases of CD4 counts up to a full year afterward. These observations led him to pilot-test a support group intervention in 1990 whose goal was to equip bereaved gay men with the psychological skills they needed to cope actively with their losses, thereby, Goodkin hoped, bolstering their immune systems. In its fifth year at the time of our interview, and by then funded by the National Institute of Mental Health, Goodkin's bereavement support group at the University of Miami included 240 men, grouped separately according to whether they were HIV positive or negative, who had lost a close friend or lover within six months prior to entering the study. Participants were randomly assigned to either an actual support group, which met for ten weeks, or to a control group that didn't meet but did get called every three weeks to see how the men were coping with their loss.

Each session of the support group was devoted to a particular topic intended to elicit responses from the group members. The first set of topics made the individual conscious of his loss through questions such as, "What is bereavement?" and "What responses have you had from the medical care community?" The next sessions explored the implications of the loss for the individual's own mortality and spirituality. Finally, the group's last stage was the "moving on" phase, when members assessed how the intervention would help them deal with the particular loss that brought them to the group, as well as with future losses, including other losses besides death, such as the loss of a job or relationship.

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After the support group's ten weeks were up, Goodkin and his colleagues followed up with all the men every six months for two and a half years to assess their psychological and physical health. Goodkin found "significant buffering" against a decline in CD4 cell count and increased natural killer cell counts in men who were HIV positive and in the intervention. He said it would be some time before he could determine whether the intervention had attained its ultimate goal: deterring progression to clinical AIDS.

In the meantime, he noted that even the men in the control group who received only phone calls seemed to benefit merely from being part of the study. Like the men who participated in the earliest studies in the epidemic, these men felt "validated" merely by having their losses recognized. As Goodkin put it, "Just being assessed about their loss and their loss burden was giving them self-affirmation that was important for them."⁷⁶⁹

New York's St. Vincent's Hospital was a welcoming neighbor to gay men in Greenwich Village long before the AIDS epidemic. In fact, the hospital was literally next door to the Gay and Lesbian Community Services Center, on West Thirteenth Street. So it was natural that when gay men in the Village began to get sick with AIDS in the early eighties, many of them went to St. Vincent's to be treated or to die. The families of these men, many of whom traveled long distances to be with their son or brother at the end of what may well have been a life of estrangement, often didn't know the men were gay. Still other survivors included articulate young friends or lovers, in touch with their feelings. The staff at St. Vincent's realized that the bereavement program they had in the hospice could be expanded to assist these people who were losing loved ones to

⁷⁶⁹. Karl Goodkin, MD, Ph.D., interview with author, Miami, 19 May 1995.

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AIDS. They trained volunteers to work, like “buddies,” with AIDS patients until they died. And they established the first bereavement groups anywhere in New York for people who had lost someone to AIDS.

Sister Patrice Murphy, a registered nurse and Roman Catholic nun, directed St. Vincent’s Supportive Care Program from the time the support groups began in 1983 until 1990. In an interview on Ash Wednesday 1995 at her home in the hospital’s staff residence, Sister Patrice explained how the support groups operated. The first of the weekly meetings was to get people to tell their stories. “That was always a weepy session,” said Sister Patrice. “Sometimes people felt they couldn’t come back after that.” The rest of the meetings followed no formal agenda because people would inevitably bring up the kinds of feelings and issues that Sister Patrice and her co-leader hoped they would address. She told me, “I think once they knew they were accepted, that what was said in the group was confidential, that we cared about the fact that they were suffering, that we could cry with them—those kinds of things I think engendered a spirit of trust.”⁷⁷⁰ Men talked about feeling that a part of them had died with their lover or friend. Some talked about parents. Others talked about not wanting to be left behind when everyone they knew was dying. Most all of them asked, “Who’s going to take care of *me*?”

When I first interviewed Sister Patrice, in 1986, I was curious to know how welcome gay men were at St. Vincent’s, a Catholic hospital, in view of the Catholic Church’s official condemnation of homosexuality, reiterated by the Vatican that very

⁷⁷⁰. Sister Patrice Murphy, interview with author, New York City, 1 March 1995.

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year.⁷⁷¹ She assured me that gay men were most welcome and had in fact been “always part of the scene” at the hospital because of its location in Manhattan’s gayest neighborhood. “My role here is a nurse, a caregiver,” she said. “I’m not here as a moralist or a judge.” She noted, however, that one of the important issues confronting the gay men who were dying of AIDS at St. Vincent’s was religion. “There is a searching,” she explained, “a grasping for spiritual comfort, a desire to discuss and grapple with issues.”⁷⁷²

The late Richard A. Rasi, a psychologist and Catholic priest in Boston who often celebrated mass for the gay Catholic group Dignity, described the spiritual issues he helped gay men and their families confront in the AIDS epidemic. For many, he said, AIDS made them ask the same question they asked when they “came out” as gay: “What’s wrong with me?” There were those whose thoughts turned to eternity when it seemed clear their future would be abbreviated. And then, said Rasi, there were the spiritual dimensions of the gay community’s support, care, and love for those with AIDS. In doing memorial services or liturgies for gay men, Rasi dealt with families he often had never met. “A lot of the work that gets done in those situations,” he explained, “is really the effects of the disease on the families—holding them and letting them know that they’re okay, that their

⁷⁷¹. Cardinal Joseph Ratzinger (today known as Pope Benedict XVI), “Letter to the Bishops of the Catholic Church on the Pastoral Care of Homosexual Persons” (The Vatican 1986). In Jeffrey S. Siker, ed., *Homosexuality in the Church: Both Sides of the Debate* (Louisville: John Knox Press, 1994), 39.

⁷⁷². Andriote, “Coping with Grief in the Time of AIDS.”

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loved one is okay and that they didn't die because God hated them."⁷⁷³

The support groups continued to meet at St. Vincent's. By the time the hospital closed, in 2010, thousands had gone through the eight-week program, meeting once a week to talk with others who understand about the losses they suffered in the AIDS epidemic. There was a monthly memorial service for all who died in the month. Once a year there was a large memorial service that brought together all the past group members. As in any alumni gathering, they reunited to compare notes about how far they'd come and gone since the last time they shared a formative experience. These alumni shared a deep bond, forged in the fires of anguish and loss. As Sister Patrice said, "I don't think anybody can really understand grief who hasn't been through it. But you can't even be hard on them because if they haven't felt the pain, how could they imagine it?"⁷⁷⁴

⁷⁷³. Richard A. Rasi, telephone interview with author, 13 December 1996.

⁷⁷⁴. Murphy interview.

THIRTY-FOUR

Since Harvey Milk's assassination in 1978, gay San Franciscans have mourned their fallen heroes in large candlelight marches that move like a dirge from the Castro district to City Hall. On the night of May 2, 1983, a dozen people with AIDS led the first of what would become an annual candlelight march, hoisting aloft a banner whose message would forever encapsulate the struggle that confronted each of them, as well as all gay people: "Fighting For Our Lives," it said. Gary Walsh, one of the city's first to be diagnosed with AIDS and the one who thought of the idea for the candlelight march, held the banner between Bobbi Campbell, the "KS Poster Boy," and Mark Feldman, an old boyfriend.

Some of the thousands who joined the march brought snapshots of friends who had died, while others carried signs that read like gravestones:

Ken Horne
Born July 20, 1943
Died November 30, 1981

Six thousand people stood in United Nations Plaza to listen to speeches by people with AIDS. Mark Feldman told the crowd, "Our president doesn't seem to know AIDS exists. He is spending more money on the paints to put the American flag on his nuclear missiles than he is spending on AIDS. That is sick." Earlier in the day, Mayor Dianne Feinstein had met with a group of men with AIDS at her office after she issued a proclamation of AIDS Awareness Week. Also that day the Centers for Dis-

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ease Control had released figures showing that the number of new AIDS cases in the United States had increased by 36 percent to 1,366 cases; 520 people were already dead.⁷⁷⁵ Candlelight marches were held the same night in Boston, Chicago, Dallas, Houston, and other cities, sparking some of the first local media coverage of the epidemic. The *New York Times* buried its own few paragraphs of coverage inside the paper, and didn't even make reference to the fact that most of those who had participated in the marches were gay men, instead describing the crowds as "mostly male."⁷⁷⁶

The newly formed PWA Coalition of San Francisco had asked Paul Boneberg to help them organize the candlelight march in San Francisco, and to get other cities to hold similar marches. Years later, Boneberg still marveled at the drive of the men with AIDS who led that first march. He said, "I can't think of another community on earth that would think that the logical response to being stricken with an unknown disease is to come out, say your name on TV, and organize a march! It directly flows from Harvey Milk, and [his saying] 'Come out, come out! Organize, organize!'"

Although a candlelight march wasn't held in San Francisco in 1984—everyone was busy planning the big march at the 1984 Democratic National Convention being held there that year—it was resumed in 1985, and organized by the newly formed gay-AIDS political group Mobilization Against AIDS. This time the PWA Coalition wanted candlelight marches not only in San Francisco and other American cities, but in other countries as well. Boneberg, who was then director of Mobilization, initially resisted getting the group involved with the candle-

⁷⁷⁵. Shilts, *And the Band Played On*, 284–86.

⁷⁷⁶. *Ibid.*, 284–86.

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light march. He recalled, "I basically said I'm here to organize demos; I don't know anything about international organizing."

But the people with AIDS persisted. "And they did it," said Boneberg. "Richard Rector and Dean Sandmeyer and others organized candlelights in something like eighteen countries." Boneberg seemed to wonder how he ever doubted the determination of those early PWAs when he added, "And that's how it was done." While he still maintained that his role with Mobilization was political, Boneberg now understood that even the candlelight march was a kind of political art form. "When I look at the candlelight and what it's done," he said, "I think maybe I was actually doing mass art. What I really was engaged in was an artistic, cultural phenomenon. In hindsight, I tend to think the cultural response of the candlelight is amazing, and speaks to the depth of soul of our community."

The candlelight march's political impact has been felt in small American towns and around the world. Said Boneberg, "The most important candlelight is not the one that's occurring in San Francisco or New York, because they are organized. It's the one that's occurring for the first time in Lynchburg, Virginia, where you've got a mom, somebody else's lover, and they get together and they're doing this thing. That is the beginning of organizing." Internationally, this ritual created by gay Americans had profound effects. Within two years after Boneberg received a letter from a doctor in Tokyo, saying that in Japan people were ashamed of AIDS and he didn't think a candlelight would ever occur, the gay movement had started in Japan and they organized a candlelight memorial. All the Japanese networks showed people carrying candles down the street. Boneberg noted that during the 1994 international AIDS conference in Yokohama, an openly HIV-positive person addressed the prime minister. As Boneberg put it, "It was astute to provide this tool to people around the world and to say, well, we have found this

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to be useful. The more repressive and closeted or fascist a country is the more useful that tool is to them.”⁷⁷⁷

In 1995, the twelfth international AIDS Candlelight Memorial and Mobilization was observed by 250 cities in 45 nations. In Washington, DC, fifteen hundred people processed from Lafayette Square—across from the White House, where candles were placed in the windows facing the square to observe the occasion—to the reflecting pool at the US Capitol. Underscoring the political nature of the march, AIDS “czar” Patsy Fleming spoke to the crowd about the cuts in AIDS funding then being considered in Congress. With her back to the Capitol, Fleming told the crowd, “We have to shine some light on what is being proposed in the building that stands behind me, because those of us who have experienced the kind of losses we have seen in the last fifteen years cannot stand still while the programs that help the people we love are decimated.”⁷⁷⁸

Shining a light on the lives of people who died from AIDS was the task of obituaries. The final news reports of people’s lives have been as politically charged a venue as any in gay people’s efforts to mourn their dead and mark the community’s losses. “After the recent bombing, our papers are filled with obituaries,” said Oklahoma City psychiatrist Larry Prater in an interview a month after the April 1995 bombing of the Alfred P. Murrah federal building. “With the bombing it’s been harder to tell who died of AIDS recently.”

⁷⁷⁷. Paul Boneberg, interview with author, Washington, DC, 17 August 1995.

⁷⁷⁸. José Zuniga, “Candlelight Vigil Draws About 1,500,” *Washington Blade* (26 May 1995).

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Even before the tragic bombing, though, it was hard to tell who in Oklahoma had died of AIDS by reading the newspaper obituaries. That's because there in America's heartland, AIDS means gay—which means gay men with HIV tend not to tell their families either that they are gay or that they have the virus. Prater said, "They're so closely linked there that to tell them they're HIV-positive is about the same as saying they're also gay." So many Oklahoma families—just like the families Randy Shilts described years earlier—often didn't know the son was gay or that he had AIDS until it was too late. Prater noted that things had improved somewhat because now at least sometimes an obituary will mention an AIDS death, or even the name of the "special friend." Still in others, he added, "there will be no clue whatsoever."⁷⁷⁹

Urban sophisticates might scoff at such provincial reticence, but even the highbrow *New York Times* at the start of the epidemic refused to use the word "AIDS" in an obituary, and eventually mentioned a dead gay man's surviving lover only as a "long time companion"—as though he'd been a paid geriatric assistant or a pet. It was only in December 1995 that the *Times* agreed to change its policy against using the word "lover" (then a more popular term among gay men than "partner") in the death notices that survivors pay to have published. When New York's Gay and Lesbian Community Services Center paid for a death notice for its deputy director's lover, the *Times* ran the notice without the word "lover," as the center had requested. The center's executive director, Richard Burns, wrote in a letter to the paper, "Despite Mr. Woodworth's expressed intention and the Center's protestation, the *Times* inserted 'life partner' when referring to Mr. Woodworth's seven-year relationship with Mr. Vilanueva in the death notice which ran Saturday, Decem-

⁷⁷⁹. Larry Prater, MD, interview with author, Miami Beach, 20 May 1995.

VICTORY DEFERRED

ber 9th.” The *Times* responded to the center’s letter by saying it had changed its policy. It reprinted the death notice, at no charge, on December 12—with the word “lover.” Clearly the policy change didn’t apply to the *Times*’ obituaries because the newspaper of record’s obituaries continued not to use the word “lover.”

In contrast to the obituaries in mainstream newspapers, which usually read like a résumé of the deceased’s education and work life, gay newspapers tended to provide a more personal view of the individual. Typically a photograph of the man accompanied an affectionate description of his hobbies, names of actual pets, close friends, a lover if there was one, and remembrances of his charms and interests along with a description of his schooling and professional accomplishments. Since so many gay people are immigrants to their home city from somewhere else—typically a small town—these obits also often mentioned the reasons the individual moved to the place where he lived and died.

The eloquence of the June 1997 obituary for thirty-nine-year-old John Howard Martindale, Jr., in San Francisco’s *Bay Area Reporter*, was typical. “John Martindale,” it said, “died peacefully in his sleep in San Francisco on June 13 of AIDS. John’s sweet nature and strong character were as present in his long battle with the disease as they were throughout his full life before it. Born in Newport Beach, Calif., John was a big-hearted soul right from his youth. He moved to his beloved San Francisco just after high school and just in time to take part in the wonderful rise of the city’s gay culture. As waiter and manager, John was a popular fixture at Vanelli’s restaurant on Pier 39. He earned a bachelor’s in business and became fluent in Spanish, enjoying long stints in both Mexico and Spain. As a hotline volunteer for Project Inform, John showed characteristic generosity with his knowledge and sensitivity. It was probably in

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the beautiful world of plants and animals, though, that John's gentle passions came through best. His gardens radiated his joy, and the love he shared with his Chihuahua, Carly, was truly endearing. John is survived by his devoted parents, John Sr. and Ann, and his loving sister, Lisa. There will be a memorial garden service at two-thirty p.m. on Friday, June 27."⁷⁸⁰

For years, the *BAR* each week included upwards of two full pages of obituaries, virtually all of them of gay men struck down by AIDS. Michael Bronski observed, "Reading *BAR* is like walking through a graveyard, or viewing the Vietnam Veterans' Memorial Wall—the only difference is that you knew these people and may have been them only a week ago." In 2009, the San Francisco GLBT Historical Society made all *BAR* obituaries since 1980 available in a searchable online archive (at www.glbthistory.obituaries).⁷⁸¹

Describing his own experience of writing obituaries for Boston's *Gay Community News* in the early and mid-eighties, Bronski said, "Despite the terrors of writing and reading obits, there is also the satisfaction, however incomplete, that something is being done. Someone's life has been noted. Some attention is being paid. Someone else may read and understand a little more of how large, how inclusive and diverse the gay world is." He added, "[I]n taking action—as well as in remembering and mourning, which are part of each obituary—the

⁷⁸⁰. Obituaries, "John Howard Martindale, Jr.," *Bay Area Reporter* (26 June 1997), 20.

⁷⁸¹. Seth Hemmelgarn, "B.A.R. Obituaries Go Online," *Bay Area Reporter* (26 November 2009), 1.

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pieces ease both the terror and the pity, and they become politically inseparable from the personal.”⁷⁸²

It is precisely this linkage of the personal and political that distinguished many memorial services for gay men who died of AIDS, especially during the eighties when the fear and stigma associated with the disease reached hysterical proportions. On a political level, as the *New York Times* has noted, the gay community’s memorials often have been “platforms for grief and celebration and the politics that surround AIDS. Participants not only cry and reminisce but rail against the government, push for more medical research and raise money to fight on.” At the same time, “The friends and colleagues who plan the services make them highly personal, saying that one of their goals is to prevent a friend or relative from turning into one more statistic.”⁷⁸³

Gay memorials served to affirm the value of gay lives, and of the deceased individual to the life of the gay community. By insisting that the word AIDS was named openly as the cause of death, gay people sought to remove the sting of what society considered a shameful death. Frequently there was more than one memorial tribute for the same man, generally because the man’s family either couldn’t make it to the memorial his friends organized in the place he lived as an adult, or because the family refused to attend a “gay” event. Even in his death, a man’s family too often continued to deny the fact of his gay life. Judy

⁷⁸². Michael Bronski, “Death and the Erotic Imagination” and “AIDS Art and Obits.” In *Personal Dispatches: Writers Confront AIDS*, 136, 166.

⁷⁸³. Mireya Navarro, “Ritualizing Grief, Love and Politics: AIDS Memorial Services Evolve Into a Distinctive Gay Rite,” *New York Times* (30 November 1994), B1.

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Pollatsek said, “I remember early on with one family there were two funerals, a funeral for the friends and a funeral for the family in a traditional church.” She noted that, particularly in the early years of the epidemic, “there was a real need to change the ritual, to stamp it in a different way. It became important that AIDS got mentioned one way or another, and that the person was gay. There was always some effort in those days, such a sense of people being on the outside, of banding together, of a community of PWAs.”⁷⁸⁴

Many gay men are known to be exceptionally creative in their lives; they certainly have been creative in the ways they’ve memorialized their own and one another’s deaths. Often men have planned their own memorial services in advance, permeated with the camp humor that has sustained gay people through the worst of persecutions, including that of a viral enemy. Pollatsek, who was not gay but had worked with and attended memorials for hundreds of gay men, recalled one memorial service that typified the untraditional, highly personal rituals often used to mark many gay men’s deaths. “I remember Steven Chase’s funeral in 1986,” she told me. “Steven gave us elaborate funeral instructions that said things like ‘By hook or by crook, my cat Sasha will be there,’ and ‘You will all drink a toast to me and throw your glasses in Tom’s fireplace.’ Tom was sweeping glass for weeks.” She said that another treat at Chase’s funeral was the batch of “Alice B. Toklas brownies” baked specially for the occasion.⁷⁸⁵

Randy Miller recalled the memorial service that Black gay filmmaker Marlon Riggs planned in detail for himself. “He was

⁷⁸⁴. Judith Pollatsek, interview with author, Washington, D.C., 27 February 1995.

⁷⁸⁵. Ibid.

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really a control queen,” said Miller, “so he had it choreographed down to the last minute. You could hear him in different parts. He had Aretha Franklin singing ‘Young, Gifted, and Black.’ You could hear Marlon considering himself young, gifted, and Black. So it was all about him and odd things that he had put together himself. You could almost hear him chuckling. There were little things like that all through the service. It was really powerful.”⁷⁸⁶

Power—specifically, personal and communal empowerment—was precisely the point of the memorials and other rituals gay people created in response to the thousands upon thousands of deaths in the community. After publishing a 1992 study of 207 bereaved gay men in the *American Journal of Psychiatry*,⁷⁸⁷ Richard Neugebauer, a psychiatric epidemiologist at Columbia University, told the *New York Times*, “The gay community has helped people deal in a more constructive way with their grief. Rather than becoming incapacitated, they became politically and socially active and put their energies into that.”⁷⁸⁸ AIDS activist and cultural critic Douglas Crimp noted that in fact many gay people transformed their grief into AIDS

⁷⁸⁶. Randy Miller, interview with author, Washington, DC, 17 August 1995.

⁷⁸⁷. Richard Neugebauer, et al., “Bereavement Reactions Among Homosexual Men Experiencing Multiple Losses in the AIDS Epidemic,” *American Journal of Psychiatry* 149 (October 1992): 1374–79.

⁷⁸⁸. Elisabeth Rosenthal, “Struggling to Cope With the Losses As AIDS Rips Relationships Apart,” *New York Times* (6 December 1992), 1.

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activism. “For many of us,” he said, “mourning becomes militancy.”⁷⁸⁹

The “militants” of ACT UP/New York had their own unique ways of memorializing their fallen comrades, empowering themselves, and pushing the political envelope all at the same time. The late ACT UP member and author David Feinberg described the group’s private memorials in *Queer and Loathing*. During the group’s Monday night meetings, members would take the floor for “mini-memorials” during which they offered personal reminiscences of the deceased. Feinberg wrote, “These are always contained, confined within the three-and-a-half hour agenda of the meetings; they generally last no longer than fifteen minutes. We end these memorials by chanting ‘ACT UP, fight back, fight AIDS!’ three times.”⁷⁹⁰

Besides its “mini-memorials,” ACT UP sponsored several “political funerals” in which the remains of one or more of its members were paraded about—either with a casket or as cremation ashes—in an effort to push the group’s agenda. The most infamous of these “actions” was the attempt by ACT UP members to conduct a funeral ceremony in front of the White House for member Tim Bailey, whose body they carried in a casket. After the police struggled with the ACT UP pallbearers and arrested Bailey’s nongay, nonactivist brother for assaulting a police officer, the group retreated and held their ceremony from atop the van that would return Bailey’s body to a funeral home in New Jersey. Though not otherwise known for under-

⁷⁸⁹. Douglas Crimp, “Mourning and Militancy,” *October* 51 (1989), 3–18.

⁷⁹⁰. David B. Feinberg, *Queer and Loathing: Rants and Raves of a Raging AIDS Clone* (New York: Penguin Books, 1994), 196, 254–65.

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statement, Feinberg concluded of ACT UP's political funerals, "The concept is unfathomable, incomprehensible, as difficult to grasp as death."⁷⁹¹

The art that gay people created in the AIDS epidemic attempted precisely to fathom the depths of our suffering, comprehend the vastness of our loss, and grasp for meaning in what seemed the pointless tragedies we experienced. In essays, films, novels, poetry, plays, performance art, photographs, and symphonies, gay people sought to tell our stories to one another and to the world, and to connect our suffering to the loss that all who share "this mortal coil" will, at some point, experience. As Armistead Maupin put it, "The bigger the calamity, the higher the art." He noted that the art of AIDS is "a healing and strengthening force," adding, "It's not a wishy-washy, airy-fairy affectation. It's a very gritty, gut-level, potent thing that not only strengthens the artist, but strengthens the recipients of the art."⁷⁹²

Many gay artists who were working before the epidemic applied their talents to the telling of the community's woeful tales. Andrew Holleran, author of *Dancer from the Dance*, devoted his attention mostly to the AIDS epidemic. But unlike Larry Kramer, who turned his post-*Faggots* "exile" to political ends by becoming an independent, chastising voice, Holleran seemed to retreat in a despair much deeper than what he expressed in his first novel, in 1978. In his third novel, *The Beauty of Men*, Holleran described the pervasiveness of AIDS in gay life and the denial that not having it elicited in many. When Lark, the novel's middle-age gay central character, and his friend Sut-

⁷⁹¹. Ibid.

⁷⁹². Armistead Maupin, telephone interview with author, 23 December 1996.

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cliffe are told by an acquaintance in New York that a mutual friend had just died in San Francisco, they were relieved to know the man had been run over by a taxicab rather than dying “of it.” Holleran writes, “That was where AIDS stood in the hierarchy of misfortune, somehow; in a class by itself—so grim its aura extended to the fact...that people who don’t have AIDS imagine somehow they’re going to die.”⁷⁹³

The disproportionately large number of gay men in the arts meant there were a correspondingly large number of AIDS deaths among the artistic professions. Many in the arts feared that the loss of so many gifted young choreographers, dancers, musicians, novelists, painters, playwrights, and poets within such a compressed time period would continue to reverberate well into the future. When ballet legend Rudolf Nureyev died from AIDS in 1993, Gordon Davidson, artistic director of the Mark Taper Forum in Los Angeles, where Tony Kushner’s *Angels in America* was first performed in a 1990 workshop, said, “The impact on the arts and culture is incalculable. The problem, aside from the horror of the deaths, is that the system by which we encounter art is a system of passing things down, and when you break the circuit the way it is being broken by AIDS, the damage may be irreparable.”⁷⁹⁴

Although not every work of art by a gay person in response to AIDS had the bite of Larry Kramer’s 1985 play *The Normal Heart*, such works typically demonstrated just how political one’s personal experience can be. By illustrating the humanity of people with AIDS and showing the excruciation of their and

⁷⁹³. Andrew Holleran, *The Beauty of Men* (New York: Penguin Books, 1996), 54.

⁷⁹⁴. David Ansen, et al. “AIDS and the Arts: A Lost Generation,” *Newsweek* (18 January 1993), 16–23.

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the community's losses, this art attempted to heal some of the wounds in gay hearts and minds inflicted by both the disease and society's disdain for gay people. In a foreword to the published version of *The Normal Heart*, Joseph Papp, the play's first producer, expressed what Kramer and other gay artists were attempting to portray in their work. Papp wrote, "[T]he element that gives this powerful political play its essence, is love—love holding firm under fire, put to the ultimate test, facing and overcoming our greatest fear: death."⁷⁹⁵

Gay people's love and loss manifested themselves in other ways, too. In 1996, Congress designated a fifteen-acre wooded dell in San Francisco's Golden Gate Park to be the site of a memorial to those who have been lost to AIDS in this country. The concept of the AIDS Memorial Grove originated in 1989 with a group of San Francisco landscape architects who were bereft at the loss of a colleague to AIDS. Word spread, and attorneys, botanists, designers, fundraisers, public planners, and other volunteers joined together to make the grove a reality. Kerry Enright, the first director of the nonprofit organization running the grove, said, "The designation of the AIDS Memorial Grove as a national landmark will not only help to raise awareness of the enormous national toll which the AIDS crisis has exacted, but it will also inform people that there is a dedicated place in the public landscape that answers a legitimate, desperate need." Even before its completion, thousands of visitors from around the world were visiting the site to grieve openly without embarrassment. Said Enright, "This is not just a place

⁷⁹⁵. Joseph Papp, in the foreword to Larry Kramer, *The Normal Heart* (New York: Penguin Books, 1985), 29.

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for mourning; it is a living and breathing space where people can experience the pathos of AIDS.”⁷⁹⁶

The air was heavy with the pathos of AIDS as more than 650,000 people gathered in Washington, D.C., on October 11, 1987, for the second March on Washington for Lesbian and Gay Rights. People with AIDS led the march, some in wheel-chairs pushed by their friends. Displayed for the first time near the post-march rallying area on the Capitol Mall was the NAMES Project AIDS Memorial Quilt. The quilt had been laid out in a solemn ceremony at dawn, its 1,920 panels covering the equivalent of two football fields.⁷⁹⁷ Those panels represented a fraction of the 24,698 Americans who had died of AIDS by then. People in the cities most affected by the epidemic to that point—New York, Los Angeles, and San Francisco—had sent panels to the NAMES Project’s San Francisco workshop in memory of their loved ones. Most of the panels were sewed with the names of young gay men.⁷⁹⁸

Many of us at the march saw the quilt as a stark reminder of why we were in Washington to protest. Like the motto of the people with AIDS who carried the banner in 1983, the hundreds of thousands gathered on the Mall near the quilt joined lesbian folk singer Holly Near in the old civil rights anthem, “We are a gentle, angry people who are fighting for our lives.” The timing

⁷⁹⁶. Cynthia Laird, “AIDS Memorial Grove Designated National Memorial by Congress,” *Bay Area Reporter* (10 October 1996), 1.

⁷⁹⁷. *AIDS Memorial Quilt*, booklet (San Francisco: NAMES Project Foundation, 1996).

⁷⁹⁸. Cleve Jones. In Joe Brown, ed., *A Promise to Remember: The Names Project Book of Letters*, vi.

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of the quilt's premiere at the march—as the presidential campaigns were getting seriously underway—was deliberate, and its presence provided a powerful symbol of the gay community's political struggle for equal rights and of the casualties of the simultaneous struggle for sexual liberation. The day of the march and the quilt's display was NAMES project founder and Harvey Milk protégé Cleve Jones' thirty-third birthday. To this day October 11 is designated "National Coming Out Day," when gay people are urged to identify themselves as such to others.

Jones recalled in an interview in San Francisco, not far from the places that inspired him, why he thought the quilt would provide an image that resonates with the American people. Jones had had to reschedule our 1995 meeting because he himself was now living with AIDS and the unpredictability of his health from one day to the next made planning difficult. He told me that he got the idea for a quilt when he and others were putting up posters for the annual candlelight march for Harvey Milk. "The *Chronicle* had a headline saying that a thousand San Franciscans had died within ten blocks of here: Almost every one of that thousand had died within ten blocks of where we were standing. But you couldn't see that, couldn't walk down the street and see death everywhere."

Jones wanted something that would provide a visual image of the toll by showing the lives behind the statistics. During the candlelight march, he asked everyone to carry placards with the name of one person who had died. Using ladders he hid in the shrubbery, Jones and his friends taped the placards on the front of the federal building. "As I was looking at the patchwork of names on the wall," said Jones, "I said to myself it looks like a quilt." The word evoked warm memories for him because his great-grandmother had sewed a series of quilts to pass on to her grandchildren. An idea was born. Jones recalled thinking, "This is such a warm, comforting, middle-class, middle-Ameri-

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can symbol. Every family has a quilt; it makes them think of their grandmothers. That's what we need: We need all these American grandmothers to want us to live, to be willing to say that our lives are worth defending."⁷⁹⁹

Besides its obvious link to the gay rights struggle, the quilt is one of the nation's most extraordinary examples of public mourning art. It is often compared and contrasted with the Vietnam War Memorial in Washington, D.C., because it represents a collective memorial for many individuals, and because of the way it draws people to publicly share their grief with others who also have lost loved ones. In America's death-denying culture, public mourning is traditionally discouraged. We are, after all, a forward-looking nation that brooks few exceptions to our view of Americans as an obsessively optimistic people. The quilt challenges the taboo of openly mourning our dead, thereby acknowledging the reality of death in life.

As a longtime political activist, Cleve Jones was clearly aware of the quilt's power. He described it with such words as "soft," "gentle," and "subversive." As he put it, "It's not ACT UP screaming in the street." Jones pointed out that the quilt has provided him and other gay people the opportunity to bring a message of compassion and even HIV prevention to places, such as high schools, that likely wouldn't otherwise be open to them. "When I go to a high school," said Jones, "I'm welcomed by the teacher, usually the principal is there. They treat me with great respect, great deference, and I speak well to these kids. I know in every class I go to there are four or five kids in that room who are going to grow up and find out they're gay. And how much of a difference it would have made in my life if when

⁷⁹⁹. Cleve Jones, interview with author, San Francisco, 2 February 1995.

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I was in tenth grade some nice-looking, well-spoken man came and talked.”⁸⁰⁰

Although the quilt helped open doorways into the hearts of “middle America,” some gay activists complained that the quilt’s political potential hadn’t been sufficiently exploited. Urvashi Vaid, for example, said the NAMES Project “didn’t do enough to politicize people.” It wasn’t enough for people to attend a NAMES Project event. “Every one of them should have been asked to lobby,” said Vaid. “Every one of them should have been asked to write letters. The project could have acted as a funnel to direct them—into AIDS Action Council or any of the other political organizations. But it didn’t do that.”⁸⁰¹

Despite criticism that the quilt hasn’t been political enough, it has by itself arguably done more to increase awareness of the human toll of the epidemic—and of the humanity of those it memorializes—than all the nation’s gay political organizations combined. For example, in 1994 alone, forty NAMES Project chapters around the United States sponsored nearly eight hundred displays of sections of the quilt, viewed by an estimated eight hundred thousand people, according to Anthony Turney, who was then the NAMES Project Foundation director.⁸⁰² When the quilt was displayed in its entirety for the fifth time in Washington, in 1996, an estimated 750,000 people viewed it over the same days in October on which it was first displayed in 1987.

⁸⁰⁰. Jones interview.

⁸⁰¹. Urvashi Vaid, interview with author, Provincetown, Mass., 29 July 1995.

⁸⁰². Anthony Turney, interview with author, San Francisco, 1 February 1995.

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As with its premiere, the timing of the quilt's 1996 display was deliberate. As Mike Smith, a cofounder of the NAMES Project Foundation who directed the display, put it beforehand, "Several weeks before critical US elections, when the spotlight is on the president and elected members of Congress, we will display the entire AIDS Memorial Quilt in Washington—to ensure that AIDS and its awful costs are given urgency on the American and international agendas."⁸⁰³ In 1989, President George H. W. Bush declined an invitation from the NAMES Project to view the quilt, though he presumably saw it as he flew overhead in a helicopter on his way somewhere else. The Reagans also had declined an invitation to see the quilt in 1988.⁸⁰⁴

In 1996, President and Mrs. Clinton visited the quilt, marking the first time a president had done so despite the quilt's proximity to the White House. During the Clintons' visit, Cleve Jones said that someone in the crowd "startled" the first couple when he called out, "Thank you for being the first president to visit the Quilt!" Both Clintons looked at Jones and said, "Surely this can't be true." He assured them it was indeed the case. Said Jones, "I'd have to say it was the greatest moment of my life" It was also Jones's forty-second birthday.⁸⁰⁵

The quilt has grown exponentially from the forty panels—including Cleve Jones's original panel for his friend Marvin

⁸⁰³. Sheila Walsh, "DC Gearing Up for Quilt's Return," *Washington Blade* (16 June 1995), 5.

⁸⁰⁴. Sue Fox, "Clinton's Agree to Chair Upcoming AIDS Quilt Display," *Washington Blade* (12 July 1996), 1.

⁸⁰⁵. Wendy Johnson, "You Can't See the Quilt Without Being Changed," *Washington Blade* (18 October 1996), 1.

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Feldman—that had been collected by the time of its first display during San Francisco’s annual Lesbian and Gay Freedom Day Parade on June 28, 1987. In 1996, the quilt consisted of some forty-five thousand panels and covered twenty-five acres on the Mall. Despite its vastness, the quilt still represented only about one in eight Americans who had died from AIDS at that point. At this point, more than eighteen million people have seen all or part of the quilt, as sections of it are displayed in hundreds of locations a year. The NAMES Project Foundation estimates that viewing the quilt in its entirety, spending only one minute per panel, would take thirty-three days.⁸⁰⁶

However the politics of mourning are defined, it’s clear the quilt has had a tremendous impact on the way many Americans think about AIDS and, quite possibly, about gay people as well. Whether the NAMES Project alone could mobilize legions of bereaved Americans into a militant force is a dubious proposition. But perhaps the quilt’s political achievement—like the gay community’s terrific losses themselves—is best measured against the broad backdrop of human life, death, and how each is regarded with respect to the other. Rather than being merely a “political instrument,” observed Richard Mohr, the quilt “both expresses and creates sacred values.”⁸⁰⁷ Pragmatic activists who insist that mourning is worthless unless it turns to militancy, miss an important point about the quilt and its lessons for human life. As Mohr put it, elegy-making and mourning are worthy in themselves because they remind us of the reasons why,

⁸⁰⁶. The NAMES Project Foundation, The AIDS Memorial Quilt, at <http://www.aidsquilt.org/quiltfacts.htm>, accessed 17 October 2010.

⁸⁰⁷. Richard D. Mohr, “The Quilt’s Celebration of 70,000 Individuals,” *Washington Blade* (11 October 1996), 41.

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“in a world where suffering regularly dwarfs well-being, life is worth living in the first place.”⁸⁰⁸

Even if the quilt were merely a tremendous, silent elegy, its power and effect would be undiminished. As it is, however, activists who downplay the quilt’s political power overlook the fact that simply mourning the deaths of gay men is a political statement in that it affirms the value of their lives as equal to those of any other human being. In too many quarters, this remains a radical notion indeed.

By adapting a traditional, even archetypal, American folk art to publicly mourn and celebrate the lives of those who have died in the epidemic, the gay people who created the AIDS Memorial Quilt did more than their share for the gay civil rights movement by showing America the pain, dignity, and humor with which its gay citizens carried the weight of their knowledge of mortality. By living as people who have been unalterably changed by our sorrows and by a new awareness of our strength, gay people—survivors—bear daily witness to the transformative power of love and loss. That witness is every bit as “political” as any march and as powerful a testimony as there is of the struggle of gay people for an equal place in the nation where we also live, love, die, and are mourned.

⁸⁰⁸. Richard D. Mohr, *Gay Ideas: Outing and Other Controversies* (Boston: Beacon Press, 1992), 126.

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*Once the faintest stirring of hope became possible,
the dominion of the plague was ended.*

ALBERT CAMUS, *THE PLAGUE*

The advent in the mid-nineties of new and stronger treatment for HIV brought renewed and strengthened hope that HIV infection might yet become a manageable illness, its horrors a receding memory. But hope also has a price, and the exorbitant price and complex regimens of the new drugs rendered this idea of “living with HIV” for too many people as chimerical as it had ever been. Nevertheless, the ability of many others with HIV to benefit from new treatments meant not only profound changes for them personally, but also for the AIDS service organizations that were created to help people who couldn’t fully help themselves. The challenge remained to integrate HIV care into mainstream health care and social service organizations—and to ensure that all gay people receive appropriately sensitive care whatever their health needs. AIDS and gay people advocating on behalf of its victims pointed out the flaws in the American health care system, and their legacy included a system far more open to the needs and demands of its “consumers.”

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But even gay people too often followed the American way of neglecting things until they fall apart, focused as they were on those whose bodies were broken by AIDS and overlooking the many more who were healthy as yet but still facing the risk of HIV infection. A new generation of prevention educators equipped gay men with information to make their own sexual and other health choices. But the same old homophobia still threatened to undermine even the best-designed prevention efforts. Community institutions were created as bulwarks against homophobia and as welcoming refuges for any and all. Even those institutions grappled with the challenge now facing gay America at the end of the twentieth century: how to remember the past, live fully in the present, and look to a future that may or may not be free of AIDS.

THIRTY-FIVE

Lawrence K. Altman, the *New York Times* medical writer who first described AIDS to the newspaper's readers twelve years earlier, wrote in June 1993, "It is one of the bleakest moments in the fight against the disease since AIDS was first recognized as a new disease in 1981."⁸⁰⁹ After the international AIDS conference in Berlin that month, Altman had observed that "only an eternal optimist" could believe that new drugs would be available any time soon to save the lives of the fourteen million people worldwide then believed to be infected with the virus that causes AIDS.⁸¹⁰ People with HIV and their doctors alike were discouraged in 1993 by the findings on AZT reported at the Berlin conference from the European Concorde study, which showed that the first drug approved in the US to treat HIV eventually lost its effectiveness when used as a "mono-therapy."

The goal of making HIV the chronic, manageable disease that scientists long had aimed to make it seemed as remote as ever. Casting about for new possibilities, researchers speculated that perhaps combining AZT with the more recently approved drugs ddI or ddC might improve the outlook. In fact, as early as 1985, at the first international conference on AIDS, researchers had discussed the possibility of using combinations

⁸⁰⁹. Lawrence K. Altman, MD, "Government Panel on HIV Finds the Prospect for Treatment Bleak," *New York Times* (29 June 1993), C3.

⁸¹⁰. Lawrence K. Altman, MD, "Conference Ends with Little Hope for AIDS Cure," *New York Times* (15 June 1993), C1.

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of drugs that would address several aspects of immune breakdown at once.⁸¹¹ Combination therapies already were being used effectively in treating other diseases, such as tuberculosis and childhood leukemia. Since there finally were in 1993 three approved drugs for HIV, it seemed to make sense to try them together.

Cut forward two years, and the beginnings of a very different picture began to emerge. In January 1995, the World Health Organization reported that there had now been more than one million AIDS cases worldwide—70 percent in Africa, only 9 percent in the US, and very likely four and a half times less than the actual number because of underreporting. The same month, David Ho, director of the Aaron Diamond AIDS Research Center in New York, and George M. Shaw of the University of Alabama in Birmingham, reported one of the most important research findings about HIV to that point. Rather than lying dormant for an indeterminate time until starting its virulent campaign of destruction, as scientists had believed for years, HIV was active from the time it infected someone. Ho and Shaw reported that, in fact, upwards of one billion new viruses are produced a day. A healthy immune system each day generates about that many CD4 cells, the main targets of HIV. For a time, the immune system keeps the virus in check; gradually, however, HIV gains the upper hand and CD4 production can't keep pace with the virus's reproduction, until the virus finally vanquishes the immune system altogether. Ho pointed out that it was now evident that the goal of drug therapy should be to inhibit the virus's ability to reproduce.⁸¹²

⁸¹¹. Cindy Patton, *Sex and Germs: The Politics of AIDS* (Boston: South End Press, 1985), 47.

⁸¹². Gina Kolata, "New AIDS Findings on Why Drugs Fail," *New York Times* (12 January 1995), A1.

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By the end of 1995, the Food and Drug Administration (FDA) had approved 3TC, another drug in the same family as AZT, to be used in combination with AZT. In early December, the agency approved saquinavir, the first of a new class of drugs called protease inhibitors. While the earlier drugs such as AZT and 3TC, called nucleoside analogues (the “nukes”), interfered with the gene-replication cycle of HIV, the protease inhibitors blocked an enzyme used by the virus at a later stage of its reproduction. “This is some of the most hopeful news in years for people living with AIDS,” said Donna E. Shalala, secretary of Health and Human Services.⁸¹³ The FDA proved it had learned its lesson about accelerated approval, taught by AIDS activists, approving saquinavir in record time. The agency broke its own record only three months later, on March 1, 1996, approving a second protease inhibitor, ritonavir, only seventy-two days after its manufacturer applied for approval. Two weeks later, the FDA approved yet a third protease inhibitor, indinavir, the most effective of the three drugs. FDA Commissioner David A. Kessler was quoted as saying, “We now have some big guns in AIDS treatment.”⁸¹⁴

Two important innovations came to prominence in 1996: the use of viral-load testing to measure the amount of virus circulating in an individual’s bloodstream and combinations of protease inhibitors with the older class of “nuke” drugs. Viral-load testing allowed doctors to tailor treatment individually to the needs of each patient. The drug combinations produced such dramatic results that even veteran scientists spoke of its being an un-

⁸¹³. John Schwartz, “FDA Approves First in New Family of AIDS Drugs,” *Washington Post* (8 December 1995).

⁸¹⁴. Philip J. Hilts, “Drug Agency Acts Quickly on a New AIDS Treatment,” *New York Times* (2 March 1996).

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precedented turning point in the treatment of HIV. Together, these two new “weapons” made 1996 a year of great moment in the history of the AIDS epidemic.

The air was electric with anticipation and excitement as scientists awaited news on combination therapies to be reported during the Eleventh International Conference on AIDS in Vancouver that July. “By trumpeting the gains in glowing terms in advance of the meeting,” noted Lawrence Altman in the *New York Times*, “a number of leaders in AIDS research and drug companies have transformed the pessimistic mood that has prevailed at the last several international meetings to one of exuberance.”⁸¹⁵ Triple-combination drug “cocktails” were the talk of the day as researchers excitedly discussed how they had successfully reduced the amount of HIV in many infected individuals to undetectable levels, with corresponding increases in CD4 counts that would seem to indicate a rebounding immune system.

“For the first time since the early days of the epidemic,” the *New York Times* editorialized after the international meeting, “scientists seem actually to be gaining ground in treating a viral menace that has been largely incurable and almost invariably fatal.” The newspaper, however, noted several caveats that had been raised about the new protease inhibitors and drug combinations, including: possible severe side effects such as kidney stones and nausea; the difficulty of taking more than fifteen pills a day, some with food and others on an empty stomach; the possibility that HIV would develop resistance to the drugs if the regimen wasn’t followed precisely; and the exorbitant cost of the drugs themselves. Add to the list the fact that the drugs were not working for everyone, or worked for a while and then

⁸¹⁵. Lawrence K. Altman, MD, “AIDS Meeting: Signs of Hope, and Obstacles,” *New York Times* (7 July 1996), A1.

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stopped, and the relatively short period of time in which the combinations had been studied. “But even after all the caveats,” continued the *Times*, “it is hard to minimize the dramatic shift in thinking that has occurred.” Of course, the newspaper noted, the drugs would do no good at all if one didn’t know his HIV antibody status. More than ever before, antibody testing was an essential first step toward getting treatment if one was infected.⁸¹⁶

Going several steps beyond the exciting possibility of managing HIV infection, scientists speculated—and news headlines prompted some, apparently, to take the speculation as fact—as to whether the drug combinations might actually eradicate HIV from the body. For the first time in the epidemic, scientists and activists alike allowed themselves to utter the word “cure,” savoring its monosyllabic elegance even as they asked a question whose implications were chilling: What if the virus continued to hide, reproduce, and develop resistance somewhere in the body where current tests can’t detect it? Writing in the *New Republic* shortly after the Vancouver meeting, noted AIDS researcher Jerome Groopman said it was too early to call the inroads made against HIV a cure. But, he added, the three-drug combinations had “cause[d] the microbe to stumble severely.” Even if a cure was not yet at hand, Groopman concluded, “the question has become ‘when’ rather than ‘if.’”⁸¹⁷

In early November 1996, two of Groopman’s patients who were having exciting results from the drug cocktails used their access to the news media to describe their personal experi-

⁸¹⁶. Unsigned editorial, “Elation, and Deflation, Over AIDS,” *New York Times* (13 July 1996), National edition, 14.

⁸¹⁷. Jerome Groopman, MD, “Chasing the Cure,” *The New Republic* (12 August 1996), 14, 16.

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ences with the new drug combinations, raising hope and stirring controversy about what many viewed as optimism that didn't jibe with the hard facts of life for most of the world's HIV-infected people. In a front-page article in the *Wall Street Journal*, the newspaper's own page 1 editor, David Sanford, described his back-from-the-brink experience made possible by protease inhibitors. "The year 1996 is when everything changed, and very quickly, for people with AIDS," wrote Sanford. "I've outlived friends and peers, and now I find myself in the unusual position of telling people how I've survived this scourge, something I never thought would happen." With his CD4 count rising and viral load continuing to fall, Sanford had found renewed optimism for the future. "I am planning to one day retire with my partner of twenty-eight years, who is HIV-negative," he wrote.⁸¹⁸

Two days after the publication of Sanford's article, a cover story in the *New York Times Magazine* by former *New Republic* editor Andrew Sullivan boldly described his vision of what happens "when AIDS ends." Sullivan acknowledged the caveats raised about the drug combinations, and then hastily dispatched them to describe the experience of having faced mortality and lived to tell about it. Because of the new drugs, and others in the development pipeline, wrote Sullivan, "A diagnosis of HIV infection is not just different in degree today than, say, five years ago. It is different in kind. It no longer signifies death. It merely signifies illness."⁸¹⁹

⁸¹⁸. David Sanford, "One Man's AIDS Tale Shows How Quickly the Epidemic Has Turned," *Wall Street Journal* (8 November 1996), 1.

⁸¹⁹. Andrew Sullivan, "When AIDS Ends," *New York Times Magazine* (10 November 1996).

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Unfortunately, Sullivan's article focused almost exclusively on people like himself: white, middle-class gay American men with private health insurance and the best medical care available. The announcement that the "end" of AIDS was at hand would certainly be a surprise to the overwhelming majority of the twenty-three million people infected with HIV worldwide at the time, most of them poor, uninsured, and fortunate merely to have access to a rudimentary drug like AZT.⁸²⁰

Sullivan was duly chastised in the news media for what credible scientists and activists agreed was, at best, a premature declaration of the epidemic's end. "We might be at the beginning of the beginning of the end," wrote AIDS reporter Mark Schoofs in an opinion article in the *Washington Post*, "but that depends on our resolve. If we let hope lapse into triumphalism, then we might well squander the promise of the new medicines and perhaps create an even more intractable epidemic." Schoofs noted that many researchers believed the new medical regimens would have only a limited benefit. Even if the new drugs could cure people, he cautioned, "it is simply folly to talk about the end of AIDS" because of the continued absence of an effective vaccine and the risk that HIV will develop resistance to the new drugs."⁸²¹

⁸²⁰. The United Nations reported 3 million new HIV cases in 1996, for a worldwide total of 23 million HIV-infected people. In the fifteen years since the discovery of AIDS to that point, 6.4 million had died; of those deaths, 1.5 million occurred in 1996. See Lawrence K. Altman, M.D., "U.N. Reports 3 Million New HIV Cases Worldwide for '96," *New York Times* (28 November 1996), A10.

⁸²¹. Mark Schoofs, "Why It's Too Soon to Declare the End of AIDS," *Washington Post* (15 December 1996), C1.

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The excitement continued to mount nonetheless, even as phrases like “cautious optimism” became the preferred way to couch one’s hopes for the new drug combinations. New York City officials made a startling announcement in January 1997. For the first time since the recognition of the AIDS epidemic in 1981, deaths in the city from the disease had dropped sharply in 1996. Dr. Mary Ann Chiasson, the city’s Assistant Commissioner for Disease Intervention Research, said the number of people who died from AIDS in New York fell 30 percent, to 4,944 in 1996, from 7,046 in 1995. Chiasson attributed the drop to the increased use of the new drugs (noting, however, that the protease inhibitors were so new that they were unlikely to have contributed significantly to the decline in 1996) and the increased availability of federal funding to pay for more and better AIDS care.⁸²²

As more exciting reports of treatment successes emerged in 1997, AIDS researchers and activists continued to caution against premature declarations of victory. “These new treatments are like hope with an asterisk,” said Los Angeles HIV physician R. Scott Hitt, chairman of the Presidential Advisory Council on HIV/AIDS.⁸²³ Besides the caveats already noted, the “asterisk” might well have been the fact that not everyone with HIV would have access to the new drugs. The AIDS drug-assistance programs in twenty-eight states didn’t yet cover protease inhibitors. Other states faced a flood of requests for the drugs that threatened to push them into a funding crisis. Some states, including Indiana and Missouri, went so far as to orga-

⁸²². Lawrence K. Altman, MD, “Deaths from AIDS Decline Sharply in New York City,” *New York Times* (25 January 1997), 1.

⁸²³. Richard Lacayo, “Hope With an Asterisk,” *Time* (30 December 1996–6 January 1997).

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nize lotteries to determine which patients would get the treatments. As New York treatment activist Bill Bahlman put it, “We don’t know what the future will bring. There’s great potential there, and we already have tremendous results. The thing is to make sure this isn’t just a couple-year lapse in the sickness and dying. The future scares me as much as it presents great opportunity.”⁸²⁴

Moisés Agosto, director of research and treatment advocacy for the National Minority AIDS Council at the time of our December 1996 interview, tempered his excitement as he described his own experience with combination treatments. “Cautious optimism” is a hard but realistic outlook when things are looking so good after you’ve had a brush with your own mortality that gives you a personal kindredness with the biblical tale of Lazarus. In fact, activists were calling experiences like Agosto’s the “Lazarus Syndrome.” When Agosto started on protease inhibitors, his CD4 cells were in the twenties, and had been under fifty for three years. He was starting to get sick and his parents came to be with him after he’d lost a lot of weight, had microsporidium, shingles, drug-resistant thrush, and esophagitis. “It was a scary moment because I had no other options for treatment,” said Agosto. Then came the protease inhibitors. “Now,” he said, “my last T-cell count was about 286—from in the twenties. And it changed my health. It was remarkable. I got weight back. I’m making plans for the future.”

Still, Agosto cautioned, realism was paramount. “I’m still afraid of what could happen,” he told me. “If my viral load starts going up, I’m going to freak out. But I had 286 T-cells four or five years ago. Who knows, if I can have that stabilize maybe four or five more years, until there are another few drugs...” His

⁸²⁴. Bill Bahlman, interview with author, New York City, 16 November 1996.

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voice trailed off. Then he concluded, “Buying time—that’s the way I personally see it.”⁸²⁵

Buying time was everyone’s goal; paying for the drugs was another story. Calling protease inhibitors the “rich man’s drug,” *Out* magazine noted that the cost of combination therapy that included protease inhibitors and other antivirals could range up to \$14,000 a year, excluding the costs of drugs to prevent opportunistic infections and expensive services such as viral-load tests, which typically cost about \$200.⁸²⁶ Describing what he called a “good news/bad news AIDS joke” in the *New York Times Magazine*, Larry Kramer noted, “For the first time an awful lot of people who thought they were dying are saying, ‘Maybe we’ll live through this plague after all.’ And an awful lot of people should be thinking, ‘If I can afford it.’”⁸²⁷

As it had been throughout the AIDS epidemic, access to information about the new treatments was still as potentially important as the treatments themselves. As *POZ* magazine founder Sean Strub told me, “From the first days of the epidemic, access to information has been equivalent to survival.”⁸²⁸ But poor people of color, among whom HIV continued to spread, typically haven’t had access to the same informational networks as privately insured, well-connected middle-class gay men. “Patients and doctors need to understand how to utilize

⁸²⁵. Moisés Agosto, interview with author, Washington, DC, 5 December 1996.

⁸²⁶. Anne-christine d’Adesky, “Rich Man’s Drug,” *Out* (August 1996), 62.

⁸²⁷. Larry Kramer, “A Good News/Bad News AIDS Joke,” *New York Times Magazine* (14 July 1996), 26.

⁸²⁸. Sean Strub, telephone interview with author, 27 June 1995.

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these drugs,” said Agosto, “because if you don’t use them properly, if you’re not following the rules, you’re sabotaging your own health.”⁸²⁹ And risking your life. Lawrence Altman pointed out in the *New York Times* that many people fail to complete even the simplest course of antibiotics for common infections. “In AIDS,” he wrote, “skipping just a few doses can be fatal because it can allow drug-resistant strains of HIV to take over.”⁸³⁰

Unfortunately, even the efforts of advocates like Agosto and the National Minority AIDS Council to educate people of color about the new treatments faced more obstacles than just the cost. For many African-Americans, the shadow of Tuskegee hung over anything to do with medicine. Many refused the promising treatments for fear that they would once again become unwitting guinea pigs. Stephen B. Thomas, director of the Institute of Minority Health Research at Emory University, said, “It doesn’t matter what breakthroughs we have. If the community doesn’t accept it, it might as well not exist.”⁸³¹ Even in California, where a generous drug assistance program enabled anyone who needed the drugs to get them, distrust of the medical system and the medicines themselves, coupled with a persistent stigma attached to HIV and the behaviors through which

⁸²⁹. Agosto interview.

⁸³⁰. Lawrence K. Altman, M.D., “With AIDS Advance, More Disappointment,” *New York Times* (19 January 1997), A20.

⁸³¹. Lynda Richardson, “An Old Experiment’s Legacy: Distrust of New AIDS Drugs,” *New York Times* (21 April 1997), A20.

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most people contract it, were making people of color miss out on the “revolution” in AIDS drugs.⁸³²

Attitudes in the hard-hit Black community were unlikely to change any time soon towards either AIDS or medicine. Nearly two full decades into the epidemic, and with an estimated one in fifty Black men, and one in 160 Black women, infected with HIV—and accounting for 43 percent of all US AIDS cases, despite being only 12 percent of the population—leaders of the Black community still ignored the reality of AIDS. “Eyes shut, Black America is being ravaged by AIDS,” said the *New York Times* in a page-1 article.⁸³³

At a Harvard AIDS Institute forum on the impact of AIDS among African-Americans, in March 1998, Henry Louis Gates, Jr., director of Harvard’s W. E. B. DuBois Institute for Afro-American Research, said, “We didn’t get any major Black leaders to come to this. These guys don’t want to touch this with a ten-foot pole.” He added, “It’s disgusting to me.”⁸³⁴ In May, the Congressional Black Caucus called for the federal government to declare a state of emergency because of the rapid spread of HIV among minority communities in the US, a symbolic move since there were no emergency funds available beyond the annual \$3 billion the government was already spending on

⁸³². Bettina Boxall, “Minorities Missing Out on Revolution in AIDS Drugs,” *Los Angeles Times* (Washington edition; 14 April 1998), 1.

⁸³³. Sheryl Gay Stolberg, “Eyes Shut, Black America Is Being Ravaged by AIDS,” *New York Times* (29 June 1998).

⁸³⁴. Rhonda Smith, “Black Ministers’ Response to HIV Called Too Slow,” *Washington Blade* (10 April 1998), 1.

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AIDS.⁸³⁵ One had to wonder: Why the sudden concern? Could it have had anything to do with the public criticism of the Black leadership's apathy by a Black leader of Gates's stature?

Things were no better among Hispanics. Accounting for more than one in five American AIDS cases—109,252 cases as of June 1997—it was only in May 1998 that a national coalition of Latino leaders met to draft a plan to fight AIDS among their people. Ingrid Duran, director of the Washington office of the National Association of Latino Elected and Appointed Officials, said, "AIDS really isn't an issue that NALEO has given much attention to...It's been seen as a gay and lesbian issue—not a Latino issue." Duran said that the 5,400-member NALEO would lead efforts to sponsor an AIDS education meeting for the twenty-member Congressional Hispanic Caucus.⁸³⁶

⁸³⁵. Sean Scully, "Black Caucus Calls for AIDS to Get 'Emergency' Attention," *Washington Times* (12 May 1998), A4. In fact, reported the *Washington Post* not long before this book's 1999 first edition, "Federal health officials are beginning a major initiative to lessen the ravaging effects of AIDS in Black and Latino communities, marking a victory for minority lawmakers who crusaded for stronger defenses against the epidemic in the nation's most vulnerable neighborhoods." (Amy Goldstein, "U.S. to Begin Minority AIDS Initiative," *Washington Post* [29 October 1998], A3). The White House released \$156 million for the initiative, which was intended to create HIV-prevention campaigns, place more drug addicts and HIV patients into medical care, and help local health workers and AIDS activists in assessing the needs of sick people.

⁸³⁶. Rhonda Smith, "Latino Leaders Start Work on National Plan to Fight AIDS," *Washington Blade* (8 May 1998), 1.

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Despite the same old denial in the nation's minority communities even as their own people were devastated by AIDS, ever-optimistic Americans proclaimed a "new era" in the AIDS epidemic. Indeed, the continuing drop in AIDS deaths in this country was astounding. National figures showed that for the first six months of 1997 alone, AIDS deaths in the country had declined 44 percent. Headlines continued to trumpet the good news: "AIDS Deaths Drop 48 percent in New York." "California AIDS Deaths Plummet 60 percent."⁸³⁷ "No obits," proclaimed San Francisco's *Bay Area Reporter* in August 1998. "For the first time since the beginning of the epidemic there were no obituaries," said *BAR* editor Cynthia Laird. "It didn't mean no one had died that week, just that no one had turned in an obit"—as people had been doing steadily for more than seventeen years.⁸³⁸

Yet other news stories revealed just how premature the victory celebrations really were. As many as half of those who had been "revived" by the drug combinations were failing.⁸³⁹ A survey by GMHC found that nearly three-quarters of its clients taking protease inhibitors had missed a dose in the previous three months—one in ten of them missed a dose on the very day they participated in the study.⁸⁴⁰ A telephone survey of 655

⁸³⁷. Lawrence K. Altman, MD, "AIDS Deaths Drop 48 Percent in New York," *New York Times* (3 February 1998), 1; Lidia Wasowicz, "California AIDS Deaths Plummet 60 percent," United Press International news wire (9 January 1998).

⁸³⁸. Cynthia Laird, interview with author, San Francisco, 15 April 2010.

⁸³⁹. Associated Press, "Setbacks for Many on Drugs for AIDS," *New York Times* (30 September 1997), C4.

⁸⁴⁰. Mark Sullivan, "Study Finds Many Miss Doses of HIV Medicine," *Washington Blade* (19 December 1997), 23.

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people revealed that 43 percent of them had not adhered to their drug treatment regimen.⁸⁴¹ As if the failure rates and non-adherence weren't alarming enough, an estimated ten to twelve million new cases of sexually transmitted infections—mostly spread in the same ways as HIV—were being reported each year to the Centers for Disease Control.⁸⁴² Throughout the world, the United Nations estimated there were now sixteen thousand new HIV infections each day.⁸⁴³

Deaths attributed to “complications associated with AIDS” would, unfortunately, continue to appear in obituaries into the foreseeable future.

⁸⁴¹. Reuters news wire, “US HIV Patients Admit They Don’t Take Drugs—Survey Results” (5 May 1998).

⁸⁴². Sheryl Gay Stolberg, “US Awakes to Epidemic of Sexual Diseases,” *New York Times* (9 March 1998), 1.

⁸⁴³. Robert Pear, “New UN Estimate Doubles Rate of Spread of AIDS Virus,” *New York Times* (26 November 1997).

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For the time being, the implications of being able to live reasonably well with HIV infection reverberated beyond the many individuals for whom the drug cocktails were having salubrious effects. By early 1997, viatical settlement companies—whose business is to wager on the imminent demise of people with life-threatening illness by buying their life insurance policies—were panicking because of so many fewer clients. Peter Freiberg reported in the *Washington Blade*, “Some firms folded, some are no longer purchasing policies from people with AIDS, and many are offering significantly less money for policies than previously. But the industry’s travails were in inverse proportion to the hope raised by the new drug treatments. Kiyoshi Kuromiya, director of Critical Path AIDS Project, an online treatment information network, said that while people with AIDS “don’t have as much of an asset” in selling their life insurance policy, they had something far better. “They have a future,” he said, adding, “I’d rather have that. I’d rather have a reason to live.”⁸⁴⁴

With the advances in treatment and new hope, AIDS service organizations, long used to assisting clients mainly during the more advanced stages of AIDS, now faced the challenge of re-tooling their services to accommodate those who were more healthy than sick, and looking forward to longer lives rather than facing certain death. As Sandra Thurman, a former director of AID Atlanta appointed by President Clinton in 1997 as his third AIDS “czar,” put it, “We’re in an incredibly pivotal time in

⁸⁴⁴. Peter Freiberg, “Viatical Industry in ‘Utter Chaos,’” *Washington Blade* (14 February 1997), 1.

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the epidemic where we are looking at how to help people live rather than how to help them die. It's a huge shift logistically as well as psychologically."⁸⁴⁵

Instead of helping clients deal with declining health, AIDS service providers were now helping at least some of them find jobs. In 1998, the city of Boston launched a "Reentering the Job Market" initiative to help people with HIV who were doing well with the drug "cocktails" go back to work.⁸⁴⁶ And in Chicago, Howard Brown Memorial Health Center and Test Positive Aware Network in 1998 formed programs to offer clients career guidance, interview skills, job skills, and legal advice on privacy rights and health care benefits.⁸⁴⁷

The "new era" in the epidemic brought a number of challenges to AIDS service organizations. Now that people were living better and longer, the giving public saw less need to donate money to fund AIDS services. As a result, Daniel Zingale, then director of AIDS Action Council, said that at least half the council's 2,400 member organizations had cut their budgets in 1997. With fewer AIDS deaths, the NAMES Project was one of the hardest-hit groups, slashing its \$5 million budget by 30 percent. In Boston, revenue from the 1997 AIDS Walk dropped \$400,000, forcing AIDS Action Committee to reduce its \$10 million budget. AIDS Project Los Angeles's 1997 dance-a-thon

⁸⁴⁵. Lynda Richardson, "A Gap in the Résumé : When HIV Loosens Grip, It's Back to the Job Market," *New York Times* (21 May 1997), A23.

⁸⁴⁶. Fred Kuhr, "Menino Proposes \$250K Increase in Boston AIDS Budget," *Bay Windows* (26 March 1998), 1.

⁸⁴⁷. Sue Ellen Christian, "Living with AIDS Means Working with It," *Chicago Tribune Online* (27 April 1998).

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brought in \$250,000 less than in 1996. After GMHC launched a campaign around the theme “Keep on walking, we’re not there yet,” more people than ever participated in the 1997 New York AIDS Walk, but they raised \$400,000 less than in the previous year. New York’s 1998 walk raised \$800,000 less than in 1997. By early 1998, the world’s oldest AIDS organization was described as “beleaguered,” as dwindling donations forced it to cut its budget from \$30 million to \$25.5 million and to eliminate some of its 260 staff positions.⁸⁴⁸

Expanding optimism and shrinking donations forced some AIDS service organizations to consolidate operations, explore alternative fundraising techniques, and provide accountability in a way they hadn’t done since the CARE act’s hundreds of millions had fertilized so many seedling groups throughout the country. The AIDS Resource Center of Wisconsin, for example, merged with five smaller regional organizations and increased its overall budget from \$7 million to \$8.5 million. Director Doug Nelson said, “There is not any question it was time for us to make sure we were the most cost-effective in our operations.”⁸⁴⁹ And in neighboring Minnesota, Lorraine Teel, director of the Minnesota AIDS Project, assured contributors that, despite “isolated naysayers” who criticized the AIDS industry, her agency’s total overhead costs were less than 18 per-

⁸⁴⁸. Reporting drawn from Peter Freiberg, “Early Signs of Funding Fatigue?” *Washington Blade* (8 August 1997), 12; John Gallagher, “Cutting Back,” *The Advocate* (3 February 1998), 37; Mark Sullivan, “GMHC Executive Director to Step Down,” *New York Blade News* (27 March 1998), 1; and Katie Szymanski, “AIDS Walk Donations Drop for Second Year,” *New York Blade News* (22 May 1998), 1.

⁸⁴⁹. Gallagher, “Cutting Back.”

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cent. “We are good stewards of donated funds,” she said, “and we are able to maximize the donor’s dollar.”⁸⁵⁰

There was more talk of “mainstreaming” AIDS services as the epidemic increased among poor people of color. AIDS Action Council’s Zingale said the organizations formed by white gay people early in the epidemic had both an opportunity and an obligation to share their experience with minority communities in particular.⁸⁵¹ Besides giving up what Gil Gerald called the gay community’s “sentimental attachment” to the organizations they created, “mainstreaming” would likely alter AIDS “exceptionalism”—the special “set aside” of funding in the Ryan White CARE Act and treatment of HIV as unique among Americans’ medical needs. Even in the early nineties, the National Academy of Sciences noted that as AIDS affected fewer white gay men and more poor, politically disenfranchised people, the exceptions that gay advocates gained for AIDS had already begun to wane.⁸⁵²

For early AIDS advocates in Washington, though, carving out exceptions for AIDS was never the long-range goal, even if that is precisely what the government did in the CARE act. Former AIDS Action Council director Jean McGuire said, “We evolved in resistance to and in the face of public neglect. But we’ll never be able to keep up with the momentum of the epidemic.” She added that integrating HIV services in mainstream

⁸⁵⁰. Freiberg, “Early Signs.”

⁸⁵¹. Rhonda Smith, “Black Leaders Chided on AIDS,” *Washington Blade* (20 March 1998), 1.

⁸⁵². Albert R. Jonsen and Jeff Stryker, eds., *The Social Impact of AIDS in the United States* (Washington, DC: National Academy Press, 1993), 27.

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organizations was always the ultimate goal.⁸⁵³ McGuire's former colleague Tom Sheridan concurred. "Building a new mousetrap just for the AIDS epidemic," he said, "was not sustainable for the long term from political or financial perspectives. There shouldn't be any clinic in America that isn't doing HIV and AIDS-related services."⁸⁵⁴

At the 1995 Seventh National AIDS Update Conference, in San Francisco, Mervyn Silverman said in a panel discussion on specialized versus integrated HIV medical care, "We have to mainstream the AIDS patient because, one, there are not enough HIV 'specialists' to care for all of them; two, everyone needs to understand how AIDS relates to their specialty; and three, setting AIDS apart makes it a target."⁸⁵⁵ Silverman elaborated in a follow-up interview, "It needs to be mainstreamed because of homophobia, people trying to compartmentalize it and not see it as a problem for them. We can't continue to have an AIDS unit in a hospital—every physician needs to care about it. At the same time, we can't normalize it like 'Cancer Month' and then forget it."⁸⁵⁶

⁸⁵³. Jean McGuire, interview with author, Cambridge, Mass., 25 July 1995.

⁸⁵⁴. Thomas Sheridan, interview with author, Washington, D.C., 24 February 1995.

⁸⁵⁵. Mervyn Silverman, M.D., speaking on a panel ("Specialty vs. Integrated Care: Can HIV Clinics Continue to Handle the Load?") at the Seventh National AIDS Update Conference, San Francisco, 3 February 1995.

⁸⁵⁶. Mervyn Silverman, M.D., telephone interview with author, 15 February 1995.

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Of course mainstreamed HIV care would mean that gay men with HIV are cared for by health care providers who aren't necessarily gay themselves. This raised the question as to whether we weren't risking going "back to the future," returning to the situation at the start of the epidemic when gay people formed their own parallel health care and social service systems because they didn't receive sensitive care by mainstream providers. Would gay men with HIV—regardless of their race—receive appropriately sensitive care? What role would HIV-specific organizations continue to play in their care?

These questions were answered in Chicago in the formation of a unique collaboration between Howard Brown Memorial Clinic and nearby Illinois Masonic Hospital. To provide HIV clients with a "continuum of care" that included a full range of medical and hospital services, the gay clinic and the hospital agreed to what amounted to a mutually beneficial affiliation. The health center offered the hospital access to HIV and other gay patients, and the hospital guaranteed to provide gay-friendly services. Eileen Durkin, Howard Brown's executive director at the time the partnership was formed, attributed the hospital's interest in the arrangement to an article about gay and lesbian health care in *Modern Healthcare*, which portrayed the gay community as an untapped and potentially lucrative market for mainstream health care providers. Besides the potential profit, Durkin said the hospital was interested in being perceived as a "good neighbor" by creating a welcoming environment for the diverse people who live in the Lakeview area.⁸⁵⁷

Besides improving and increasing HIV health services, then-board president Frank Pieri noted that the arrangement allowed Howard Brown to expand its range of services to address the many other health concerns gay people have besides HIV.

⁸⁵⁷. Eileen Durkin, interview with author, Chicago, 1 June 1995.

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“There are more and more men who are getting older now,” he said, “who have been essentially ‘out’ since their early twenties, for most of their lives. As they get older, and as they have other health concerns, I think they are going to demand services that are gay-friendly.” Pieri pointed out that gay men in their forties and fifties have the same health risks and concerns—such as prostate cancer and heart attacks—as their heterosexual counterparts. Yet, Pieri added, “All of these issues have not been looked at because we have been so overwhelmed by AIDS, so preoccupied. It really has caused us to be so narrow-focused because it has been so overwhelming.” But other health concerns would have to be addressed, because of course death is the final issue in every life. As Pieri put it, “It’ll be interesting to see when people start to lose their lovers in twenty or twenty-five years to a heart attack if that’s going to be acknowledged as being as much of a loss as a lover lost to AIDS at forty. Is one loss perceived as more tragic than another?”⁸⁵⁸

Or, to rephrase the question, is one serious health problem more important than another if each is disruptive, even threatening, to its respective sufferer’s life? Should a gay man with a heart problem get a different level of care than another gay man who has HIV? Should a lesbian have to settle for possibly insensitive care by a mainstream provider because the gay health clinic is so overwhelmingly focused on HIV care? In society at large, the question is whether anyone, no matter what their diagnosis or medical need, should receive less than the level of services carved out specifically for people with AIDS. Ken Mayer, medical research director at Boston’s Fenway Health, said, “There has to be more to life than AIDS.”

⁸⁵⁸. Frank Pieri, MD, interview with author, Chicago, 3 June 1995.

VICTORY DEFERRED

Clearly, AIDS brought in resources to help build the expertise and capacity of the gay health clinics. But, Mayer noted, “If you don’t take into account the fact that there are next generations, there are survivors, and a community grieving,” you lose sight of the need for ancillary services, such as mental health services, as well as the reality of most gay people’s lives. Given the range of health needs beyond HIV that are as varied as the people who have them, Mayer told me, “It becomes ludicrous to build all these programs for the community you serve around this one disease. This is *one* disease that has an impact, and people have complex lives.”⁸⁵⁹

It wasn’t only because HIV was so prevalent among gay men that it overshadowed other gay health services. Funding, both from the federal government and private sources, was far more abundant for HIV services than for other gay or lesbian health needs. At the same time, the fact was that fundraisers spent most of their time raising AIDS dollars because the issue was visible and the money there for the asking. For example, of the \$12.3 million spent by Washington, D.C.’s Whitman-Walker Clinic on programs in fiscal 1995, only \$791,788—about 6.4 percent—went for non-HIV programs including lesbian, mental health, and alcoholism services. Ninety-eight percent of the clinic’s \$8.4 million in government grants, United Way, Combined Federal Campaign, and donations from clients was designated for AIDS services. Whitman-Walker’s then-medical director, Peter Hawley, said, “AIDS is so overwhelming, consuming, and visible that I think sometimes we lose sight, even those of us who work here, of all the gay and lesbian-specific things we’d like to do.” But the clinic’s then-acting director of development estimated that less than 10 percent of his department’s

⁸⁵⁹. Kenneth Mayer, MD, interview with author, Boston, 25 July 1995.

PART 10: VICTORY DEFERRED

time was spent on non-AIDS fundraising.⁸⁶⁰ This begged the question: Was there so little money for non-AIDS gay and lesbian health programs because it was unavailable—or because Whitman-Walker fundraisers spent so little time trying to generate it?

There certainly seemed to be a greater interest, in the mid-nineties, in broader gay and lesbian health issues in other quarters. Christopher J. Portelli, executive director of the National Lesbian and Gay Health Association (NLGHA) at the time of our 1995 interview, said that gay health clinics and other health care providers that constituted the association's membership were in fact recognizing that while HIV would be with us for the foreseeable future, they also needed to address other health concerns of gay men and lesbians. "We're soon going to see a new mission of these lesbian and gay health clinics," said Portelli, "as we begin to deal with the fact that HIV and AIDS are not going to go away, and that we need to take care of our health needs and the problems we have with access to health services, and to become model institutions, if you will, of services to our community of an entire panoply of primary care needs, not just HIV/AIDS-related services."⁸⁶¹

The American Medical Association itself took a stronger interest in the health needs of gay people. In a 1996 report, the AMA urged physicians to make a greater effort to "recognize" when a patient is gay. The AMA's Council on Scientific Affairs noted that as few as 11 percent of primary care physicians routinely take a sexual history from their new adult patients. With-

⁸⁶⁰. Sue Fox, "Whitman-Walker Revisits Its Mission," *Washington Blade* (24 May 1996), 5.

⁸⁶¹. Christopher J. Portelli, interview with author, Washington, DC, 3 April 1995.

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out the information provided by a frank and nonjudgmental sexual history, the AMA noted, doctors often failed to “screen, diagnose, or treat important medical problems,” including HIV and other sexual diseases.⁸⁶² Joe O’Neill, the principal author of the AMA’s new policy on gay and lesbian patients, noted that although there are few physiological differences between gay people and heterosexuals (there are different manifestations of sexually transmitted diseases, and different risks for certain cancers among lesbians) “ultimately the most important issues are around access to care, and on the psychiatric or psychological end.” The greatest change in the AMA’s policy, he said, was in “not medicalizing or pathologizing the homosexual patient.”⁸⁶³

Two and a half decades after gay people convinced the medical establishment to view them as “normal,” the nation’s leading medical organization finally acknowledged that physicians need to educate themselves about the health needs of their gay and lesbian patients.

Chris Portelli saw the shift in the AMA’s position as the result of a “second wave” among health care providers serving gay people, stemming from the recognition that “AIDS isn’t an isolated and single problem, but rather it’s connected to our whole body, our whole self, and how we approach life.” Besides AIDS, though, he said it also was due to a growing number of gay and lesbian health care workers “coming out,” and an increased number of gay health programs throughout the country. He also noted that one of the most crucial factors in raising the gay

⁸⁶². Lisa Keen, “AMA Urges Doctors to ‘Recognize’ Gay Patients,” *Washington Blade* (3 May 1996), 19.

⁸⁶³. Joseph O’Neill, MD, interview with author, Washington, DC, 29 August 1995.

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community's awareness of broader health issues was a political one.

The election in 1992 of Bill Clinton, after his overtures to the gay community during the campaign and his promise to reform the nation's health care and insurance system, raised the hopes of gay and lesbian health care professionals that at last the health needs of gay people would be taken seriously in a reformulation of the system many Americans found so lacking. Portelli said there was much excitement that finally the government "would begin to listen to the story about how, in the midst of government neglect, the community learned to mobilize and take care of itself." He added, "We all hoped, upon hearing that story, the government then would fling open its coffers and help us go the next step, which would be to shore-up that self-care and all of those nonprofit health centers that, at that point, were surviving on private donations and very little government assistance."⁸⁶⁴

But then, as Portelli put it, the great national discussion about health care reform in 1993 "went nowhere." Those with vested interests—mainly the insurance industry—pumped millions of dollars into a campaign aimed at maintaining the status quo. Just as suddenly as Bill Clinton the candidate had proclaimed health care the nation's number one concern, Clinton the president let this concern be pushed back out of sight and out of mind—though it was very much on the minds of the forty-one million uninsured Americans, and the millions more who had been herded into managed care plans and HMOs whose business it is to make profits by spending as little as possible

⁸⁶⁴. Christopher J. Portelli, telephone interview with author, 6 January 1997.

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for actual health care.⁸⁶⁵ For people with HIV, as for anyone affected by chronic or life-threatening illness—especially those who are poor—health care and insurance continued to be priorities of the first order, even if they were no longer a national priority.

Though there have been significant improvements in the level and variety of HIV-specific services available under the Ryan White CARE Act, the epidemic highlighted the flaws in the nation's health and insurance systems. Early in the epidemic, Ginny Apuzzo warned at a congressional hearing, "This disease, left unchecked, will bring down health care in America." Even though it didn't exactly bring it down, AIDS did raise important questions about the nation's health care system and its ability and willingness to respond to a public health catastrophe. Apuzzo, who became the highest-ranking openly gay staff member in the Clinton White House, told me, "The epidemic certainly confronted this country—the richest, most advanced country in the world—with the fact that it was not prepared to deal with a public health emergency." While she believed the federal government ignored AIDS as long as possible because of those it was affecting, Apuzzo, like other politically astute advocates, saw the situation in broader terms. "I believe that AIDS is every single crisis this society has looked at and ignored historically," said Apuzzo. "I believe it's sexist. I believe it's racist. I believe it's homophobic. I believe that the fact of AIDS is home-

⁸⁶⁵. Peter T. Kilborn, "Voters' Anger at HMOs Plays as Hot Political Issue," *New York Times* (17 May 1998), 1; Robert Pear, "Government Lags in Steps to Widen Health Coverage," *New York Times* (9 August 1998), 1.

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lessness and drug addiction. It's all the things politicians have said they want to address and never touch."⁸⁶⁶

Tim Westmoreland, who organized the early congressional hearings on AIDS, said the main flaw in the health care system that AIDS highlighted is its emphasis on acute illness rather than early intervention and prevention. "We have a health care system whose financing schemes are focused on taking care of people in their last stages of death and dying," he told me. Even AIDS advocates and service providers focused mainly on caring for people who were already infected with HIV, particularly in the later stages of the disease. But whether it's the federal government, insurance companies, or AIDS advocates, Westmoreland said, "It's not an accident that this occurs in a nation where we don't fix our bridges until they fall down on the highway. It's a national thing, not just in health, it's in everything that we don't do something until it's a crisis."⁸⁶⁷

Former AIDS Action Council director Dan Bross told me in 1995 that the organization seemed to face an uphill battle in getting AIDS service organizations to understand the relevance of their work to broader discussions of health care. "It's difficult to get ASOs to see their interest in legislation and policy discussions that don't have 'AIDS' specifically on them," he said.⁸⁶⁸ Building strategic alliances with non-AIDS organizations would be essential to ensuring that HIV services continued to

⁸⁶⁶. Virginia Apuzzo, telephone interview with author, 8 August 1995.

⁸⁶⁷. Timothy Westmoreland, interview with author, Washington, DC, 18 July 1995.

⁸⁶⁸. Daniel Bross, interview with author, Washington, DC, 17 February 1995.

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receive attention and funding. In the larger scheme of things, noted Jean McGuire, the most important issue behind discussions of reforming any of the components of the nation's health and social welfare systems was something as intractable as it is ignored. "The truth," said McGuire, "is that if our systems really want to learn from what happened in AIDS, they have to take up poverty, and I don't see that happening. After we saw such a defeat with health care reform, I think one thing that will have to happen is things will have to get much worse before there's a will to change them."⁸⁶⁹

Prompted by the broader issues that AIDS has raised about America's health care system, the Robert Wood Johnson Foundation by the mid-nineties had returned to its pre-AIDS focus on broad, systemic health issues rather than focusing specifically on single diseases such as AIDS. The foundation that led both the nation's private philanthropies and the federal government to fund AIDS services recognized that AIDS is in many ways a case study of the larger issues in the health care system in general, including access to care, the drug approval process, antidiscrimination protection for people with chronic illness or disabilities, and the linkage of health insurance to employment. Paul Jellinek, then RWJ's program vice president, explained, "We began to realize that in every case we were running up against the same systemic problems. While you might be able to get a Ryan White CARE Act—by definition an 'emergency,' and exception to the rule—there were no real changes to Medicaid, for instance, and you still had to wait two years for home and community services." Jellinek said RWJ began to advocate for the kinds of policy changes that benefit people with all kinds of health challenges. He pointed to the Americans with Disabilities Act as an example of reform that, for RWJ, "represents a higher level of change" because it bene-

⁸⁶⁹. McGuire interview.

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fits people with a variety of disabilities rather than any one group.⁸⁷⁰

Cliff Morrison recalled that when he traveled throughout the country to work with local communities as part of RWJ's AIDS program in the late eighties, "People would say AIDS would be the straw that broke the camel's back." More than anything, he said, the AIDS epidemic "highlighted the cracks and flaws in the system." True as this was, people like Morrison found ways to fill some of the cracks and minimize the flaws. When Morrison created the AIDS unit at San Francisco General Hospital, in 1983, the unit's client-centered approach was viewed as a radical departure from the usual physician-centered approach to health care. But, said Morrison, "I kept saying to people I think this can be a model for other things in the institution, doing what we do for these patients for *all* patients. People were asking whether I was coddling this particular group of patients, bending over backwards. I said no, attitudes in health care had to change."⁸⁷¹

If their long-term viability was in question, the AIDS service organizations formed by gay people certainly provided at least partial and impressive solutions for the short term. As AIDS fundraising pioneer Michael Seltzer put it, "We showed some of the solutions of the health crisis in America through the organizations we put in place that were community-based, volunteer-driven, and provided low-cost health-care-related services that kept people out of expensive hospitals. That's something we as lesbian and gay people can be proud of. Our agencies are

⁸⁷⁰. Paul Jellinek, telephone interview with author, 10 February 1995.

⁸⁷¹. Cliff Morrison, telephone interview with author, 15 August 1995.

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models for better health care delivery for this country.” What’s more, noted Seltzer, AIDS advocacy provided a model for people with other kinds of diseases and health concerns. “Now you have people with breast cancer using ACT UP tactics,” he said, “because we demonstrated that people have to take control of health care.”⁸⁷²

As both a onetime target of ACT UP and the federal government’s top AIDS scientist, Tony Fauci told me that gay people certainly were effective advocates and left a powerful legacy for others. Although there had been some degree of consumer activism in health care before AIDS, Fauci said, “I think the gay community has brought that to its now prototypical art form for a number of reasons. It’s dangerous to generalize, but fundamentally the gay community that’s evolved is a very competent, highly intelligent, well-placed, experienced, politically adept group. So when you get a group like that whose lives are on the line, and they decide they want to become consumer activists, they become one hell of a consumer activist!” Whereas advocates for other diseases typically are heterogeneous—“You’ve got old people, young people, people who are at various socioeconomic levels,” said Fauci—the majority of those advocating on behalf of AIDS benefited from belonging to the gay community. “You put the gay community together,” he said, “and you have a very highly polished, educated, well-placed group that, as a group, has been more effective than many other consumer ‘groups’ were.”⁸⁷³

⁸⁷². Michael Seltzer, interview with author, New York City, 4 March 1995.

⁸⁷³. Anthony Fauci, MD, interview with author, Bethesda, Md., 14 April 1995.

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As effective as the community may have been, though, heightening consumer awareness of health care issues has been merely a by-product of gay people's efforts to bring attention to AIDS and the flaws it revealed in the health care system. For gay men and lesbians, the more fundamental issue has consistently been that of fairness and equality for all citizens in the far bigger enterprise known as the United States of America. As former GMHC director Tim Sweeney put it, "We are working toward a transformation so that, hopefully, next time there won't be such social bias when it comes to a disease."⁸⁷⁴

But the social bias against gay people, and political bias against disturbing the status quo, continued to prevent the kinds of reforms that would make AIDS, and any other health emergency that might come along, a top priority as well as a situation that can be managed effectively by a well-designed and equitable health care delivery system.

Paul Boneberg, the early director of Mobilization Against AIDS and today the director of San Francisco's GLBT Historical Society, likened the role of gay people in the AIDS epidemic to that of the "canary in a coal mine" used by miners to test the safety of the air in a newly opened shaft. If the canary dies, the miners leave and try a different approach. He explained, "We're like the canary saying, 'Hey, trouble! There's a problem here.' We're saying it when one canary dies, and they keep going. Then another canary dies. And that's exactly what's happening to our people. They get sick, and the last thing the canary says is, 'Be careful, take care of yourself, it's really bad.' And nobody wants to listen to the canary." For whatever reason—though it's almost always money and politics—Boneberg added, "Those

⁸⁷⁴. Timothy Sweeney, interview with author, New York City, 2 March 1995.

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miners want to move forward to the point that they don't care that the canaries are all dying, or what's being said."⁸⁷⁵

How many more "canaries"—gay men, poor people of color, those considered "expendable"—would have to die before the United States finally found the political will to try to save them? What would it take before the nation's leaders did something that truly mattered in the fight against AIDS and other life-threatening illnesses, such as funding realistic and useful prevention efforts? Or creating a health care system in which people with a life-threatening illness don't have to worry about losing their health insurance when they become too sick to work? Or demanding fair pricing of drug treatments and providing funding support so that no one who needs them will have to go without them? Would all the "miners" have to be affected in a more personal way?

⁸⁷⁵. Paul Boneberg, interview with author, Washington, DC, 17 August 1995.

THIRTY-SEVEN

Lost in the late-1990s excitement over the new combination treatments for HIV was the fact that “men who have sex with men” continued to account for the largest proportion of new HIV infections in the country,⁸⁷⁶ and that there continued to be a lack at the national level of any real emphasis on prevention strategies that work for these men. Even in the gay community, there was a resounding lack of passion for prevention, despite the fact that vastly more gay men were at risk for HIV infection than those already infected.

In a 1996 article in the *Washington Blade*, Tom Coates, then director of the AIDS Research Institute and the Center for AIDS Prevention Studies at the University of California–San Francisco, and Mike Shriver, then the policy director for the National Association of People with AIDS, noted that gay men had done well in arguing for the “right” to HIV treatment. But, they asked, “What about the right to be protected from HIV in the first place?” The new treatments are exciting and should be pur-

⁸⁷⁶. Centers for Disease Control and Prevention, *Morbidity and Mortality Weekly Report* 47 (24 April 1998). “Men who have sex with men” accounted for 32 percent of new HIV diagnoses between January 1994 and June 1997. An additional 28 percent, overwhelmingly male, are noted as having “unreported” risk. Upon investigation, the CDC has consistently found virtually all of such males to have been infected with HIV via homosexual sex or injection drug use, stigmatized behaviors that are always underreported. Taken together, then, “men who have sex with men” continued to account for well over half the new HIV infections in the US

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sued wholeheartedly, said the HIV-positive authors, adding, “Blindly running after the promise of a cure, regardless of tantalizing hope, is never to be an excuse for abandoning HIV prevention.”⁸⁷⁷

As viral loads declined with the use of protease inhibitors and drug “cocktails,” so did the practice of safe sex, at least for some men. Almost as soon as it was revealed that the amount of HIV in the body could be suppressed to undetectable levels in some people, the question arose as to whether it was now safe to have unprotected intercourse—assuming that a low viral load meant a low chance of transmitting HIV (notably, this was only an assumption).⁸⁷⁸ Michael T. Isbell, then associate director of GMHC, said, “The very hopeful developments around the protease inhibitors may make our jobs as educators even more difficult.”

Besides the premature “all clear” some inferred from the promising effects of the new treatments, the new challenge to

⁸⁷⁷. Thomas J. Coates and Michael Shriver, “In the Race for a Cure, Prevention Must Persist,” *Washington Blade* (29 November 1996), 31.

⁸⁷⁸. Donald Abrams, MD, “A Load Off His Mind,” *POZ* (March 1997), 105. Dr. Abrams, assistant director of the University of California–San Francisco AIDS Program at San Francisco General Hospital, noted, “As the drugs have been widely available by prescription for just about a year, the duration of their potency and the real clinical meaning of having HIV RNA loads driven below the level of detection of the assay remains to be seen. One thing’s for sure—having an ‘undetectable’ viral load does not mean an individual is no longer able to transmit HIV to others! For now, an ounce of prevention is still worth a pound of cure.”

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prevention educators was in part the result, oddly enough, of the educators' own success in giving hope to HIV-positive people. Ben Schatz noted, "The HIV service sector has been saying, 'You can have a full, vibrant life and be HIV-positive.' The more people believe this to be true, the less likely they are to believe that contracting HIV is the worst thing that can happen to them."⁸⁷⁹

Others also challenged the message about living and "thriving" with HIV. If it's such a seemingly benign condition, they asked, why bother trying to avoid contracting HIV?

"We talked about 'living with HIV' or 'living with AIDS,'" said psychologist Walt Odets. "If these men are thriving with AIDS, what's so important about my not having HIV? Saying these men are thriving with AIDS, but it would be better if you thrived without it got awkward." To avoid the awkwardness, prevention messages tended not to distinguish between HIV-positive men and those who were uninfected. Formulated before the HIV antibody test made it possible to know who is and isn't infected, the messages blurred the lines so as not to make those with HIV feel "left out" by aiming to keep HIV-negative men uninfected. But, said Odets, "We're not going to keep men negative by saying you're going to have to live with the same limitations that HIV-infected people live with because that's the only socially acceptable way."⁸⁸⁰

Odets argued that HIV-negative men were for too long "abandoned" because of the necessity to care for those with HIV and AIDS. But the epidemic affected HIV-negative men

⁸⁷⁹. David W. Dunlap, "In Age of AIDS, Love and Hope Can Lead to Risk," *New York Times* (27 July 1996), 7.

⁸⁸⁰. Walt Odets, interview with author, Chicago, 2 June 1995.

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profoundly, he said, even if they were not infected. He reasoned that if we are serious about preventing new infections, prevention education must accept that people are going to make individual choices based on their own and their partner's HIV antibody status, their understanding of the information available to them, and their personal values. Odets contended that prevention aimed at uninfected men—primary prevention, as opposed to secondary prevention which targets the already-infected—must acknowledge the psychological realities of being a gay man at a time when AIDS was so closely identified with gay men that many used the terms “AIDS community” and “gay community” as though they were synonymous.

To illustrate the point, Odets recalled a focus group conducted in San Francisco to investigate the psychological issues with which gay men were dealing. After an HIV-positive man complained about uninfected men “whimpering all the time about survivor guilt,” Odets said an HIV-negative man pointed out that, although he didn't have HIV, he did have ten or eleven dead friends and a dead lover. “I don't know what you want to call that,” Odets recalled the man saying. “But I feel like I've got a problem, too.”⁸⁸¹ Odets likened uninfected men to a family's “good child,” presumed not to have any needs by parents who are preoccupied with other problems, possibly another child who is sick or needy. But, he contended, anxiety, depression, loneliness, and homophobia—now even more insidious because of a common association in the minds of many, including some gay men, of homosexuality with a lethal disease—are serious needs that must be attended to if gay men are to remain uninfected and survive the epidemic.

Tom Coates said prevention efforts had to become more sophisticated, incorporating what is known about motivation

⁸⁸¹. Odets interview.

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and behavior from the behavioral sciences, and including a variety of approaches. “As the epidemic evolves,” he told me, “the reasons people have unsafe sex also change over time. What we don’t understand is what’s going to motivate people to stay safe in the long haul. The only way we can do that is by constantly keeping our ear to the ground, talking to people.”⁸⁸²

As important as listening to people’s concerns, though, Coates said accountability in the community and individual responsibility are two key determinants of whether the gay community will continue to reduce, if not eliminate entirely, new HIV infections among gay men. Whatever one’s personal view of sex clubs, for example, Coates said it was incumbent upon the community to discuss their pluses and minuses. Speaking during our interview of the Crew Club in Washington, DC, Coates said, “Maybe as a community we need to get a grip, be controversial, challenge one another. Should this bathhouse on Fourteenth Street be open? Is it a very good thing for this community?” On a personal level, noted Coates, the community hasn’t told gay men to find out, first of all, whether they are positive or negative, and, if positive, to care enough for other people, their brothers, not to want to infect them. On the other hand, fear of alienating those who are infected has kept the community from telling the uninfected their lives will be better by staying uninfected. “I think we fear our community is too fragile to withstand that kind of division,” said Coates. “But if we’re a strong community, we ought to be able to tolerate that kind of diversity.”⁸⁸³

The matter of either personal or communal responsibility has not been popular in a community that prizes sexual “free-

⁸⁸². Thomas Coates, interview with author, Washington, DC, 16 May 1995.

⁸⁸³. Coates interview.

VICTORY DEFERRED

dom.” Many men believe it to be the responsibility of the receptive partner in anal intercourse, if he is HIV-negative, to insist his partner use a condom. For example, nearly a third of the men in one study who knew they were HIV-infected at the time they engaged in unprotected anal intercourse reported thinking, “I may be infected already, but if this guy is willing to fuck without a condom that’s his affair. I’m not responsible for him.” At the same time, almost one in five uninfected men reported thinking, “If this guy was really infected, he’d be a lot more careful about taking a risk than he’s being now. The fact that he’s willing to fuck without a condom means he can’t be infected.”⁸⁸⁴ Strangely, the views of both negative and positive men echoed the heterosexual male chauvinism that sees women as responsible for birth control—only in this case, with two men involved, each assuming the other should be the responsible one, the stakes are considerably higher than an unwanted pregnancy.

Among those who challenged the “political correctness” that was loath to insist upon responsibility by the HIV-positive partner was a gay man who admitted to episodes in his own sexual history of not informing his partners that he was infected. Washington, DC, AIDS activist Greg Scott said, “None of us, when we go for testing and counseling, are truly told that we’re supposed to be responsible—that we, as HIV-positive people, have an enormous, grave responsibility in this. A lot of the politics of it have been about a fear of stigmatizing positive people. It’s an attempt to equalize all people in this fight, but it’s a lie, because

⁸⁸⁴. Ronald S. Gold, M.J. Skinner, M.W. Ross, “Unprotected Anal Intercourse in HIV-Infected Gay Men,” *Journal of Sex Research* 31 (1994): 59–77.

PART 10: VICTORY DEFERRED

those of us who are infected have very different responsibilities than those who are not infected.”⁸⁸⁵

Of course personal responsibility implies individual choice, which means that some people will make different choices than others, based on the same information and their own values. If they are to be held accountable for their choices, those choices also must be respected, even though they may differ from the choices that prevention educators might like them to make. As Eric Rofes put it, “Equating education with prevention and giving lip-service to individual agency in sexual matters is the core contradiction of safe sex campaigns.” He added, “Education under democracy aims for people to govern themselves, invent their own lives, and accept responsibility for their actions.”⁸⁸⁶

In recognition of the individual choices and differences in gay men’s sexual practices, the terms “harm reduction” and “negotiated safety” came up regularly in the nineties in discussions about reshaping HIV prevention for the foreseeable, AIDS-haunted future. Simply described, harm reduction, an approach long used in the treatment of substance abuse, aims to reduce the negative effects of harmful behavior. If a man is going to engage in unprotected sex, for example, the potential harm (HIV infection) could be reduced substantially by having less risky unprotected oral, rather than extremely high-risk unprotected anal, sex. Sexual partners with the same serostatus are said to negotiate safety when they agree not to use condoms during intercourse, since for two uninfected men, HIV is

⁸⁸⁵. Michelangelo Signorile, “HIV-Positive and Careless,” *New York Times* (26 February 1995), E-15.

⁸⁸⁶. Eric Rofes, *Reviving the Tribe: Regenerating Gay Men’s Sexuality and Culture in the Ongoing Epidemic* (New York: The Harrington Park Press, 1995), 197, 199.

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not present, and for two positive men it is already there so neither risks becoming infected. One Australian study found that in fact negotiated safety (today more commonly referred to as “sero-sorting”) was widely used by gay men, particularly among couples in which both partners were seronegative.⁸⁸⁷

In 1995, Boston’s AIDS Action Committee launched an HIV prevention campaign for gay men that respected their right to choose their sexual practices, and helped inform their choices by providing frank information about the differences in possible risk between oral and anal sex. The campaign was innovative, even radical, in that it acknowledged the realities and ambiguities of gay men’s lives in the ongoing epidemic, rather than the kind of black and white, all-or-nothing approach that prevention educators had used for years. In a series of ten small posters, targeted to gay men of different ages and races, and placed in the men’s rooms of gay bars, AIDS Action Committee offered messages such as, “Oral Sex *Is* Safer Sex...Oral sex is much less risky than anal sex. Unprotected anal sex is responsible for almost all HIV transmission between gay men. If we all agree to use condoms when we have anal sex, we could end this epidemic.” The risk reduction campaign, aimed at both infected and uninfected men, emphasized the importance of remaining HIV-negative, using images of both negative and positive men to convey the message. One poster pictured a man, probably in his late twenties, who says, “Honestly, I wish I were negative again...If you are negative—stay that way.”

Although oral sex has been one of the “gray” areas of sexual behavior—low-risk but not zero-risk, as the Gay and Lesbian Medical Association deemed it in 1996—some doctors and

⁸⁸⁷. S. Kippax, J. Crawford, M. Davis, et al. Sustaining Safe Sex: A Longitudinal Study of a Sample of Homosexual Men, *AIDS* 7 (1993): 279–82.

PART 10: VICTORY DEFERRED

AIDS educators resisted saying so frankly lest gay men do with impunity what virtually all of them had been doing anyway throughout the epidemic: having oral sex without condoms.⁸⁸⁸ AIDS Action Committee's founding director Larry Kessler said

⁸⁸⁸. The issue of oral sex has engendered considerable argument among AIDS educators, and confusion among ordinary gay men. While Boston's AIDS Action Committee advocated oral sex as a safer alternative to unprotected anal intercourse, Washington, D.C.'s Whitman-Walker Clinic, for example, continued to recommend that men use condoms if they engaged in oral sex. When the Gay and Lesbian Medical Association in March 1996 recommended that oral sex be classified as "low-risk," Benjamin Schatz, then the group's executive director, said, "We're not saying [oral sex] is zero risk. We're saying the overwhelming cause of the spread of HIV among gay and bisexual men is unprotected anal intercourse." On the other hand, Dr. Peter Hawley, medical director of Whitman-Walker Clinic, said, "Our stance is that oral sex is a risk." Although he conceded that it "may be qualitatively less risk than anal intercourse," Hawley said the clinic still recommended that gay men use a condom with either oral or anal intercourse. ("Gay Doctors Say Oral Sex Risk is 'Low,'" *Washington Blade*, 30 March 1996, 23). The different emphases of the Boston and Washington, D.C., groups represent the two poles of the debate. AIDS Action Committee recognized the right of gay men to choose their sexual behavior while guiding them toward a safer choice, while Whitman-Walker Clinic continued the widely used approach to prevention education that advocates only absolutes. It is this author's experience—as a former long-term resident of Washington, D.C., and observer of both Whitman-Walker Clinic's prevention programs and of gay men's sexual behavior—that the overwhelming majority of gay men in the city never heeded the clinic's counsel on oral sex, even as they (mostly) seemed to do so by using condoms during anal intercourse.

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at the time that those who saw the campaign as controversial missed the point. “Some people think we’re pushing oral sex,” he said,” and miss the risk reduction nature of it all.”⁸⁸⁹

In addition to the poster campaign aimed at reducing “harm,” AIDS Action Committee aired a thirty-second public service ad on local television stations, intended to increase the self-esteem of gay men. Brian Byrnes, then director of AIDS Action Committee’s gay male education program, said, “It is often difficult for us to convince gay men at risk of HIV infection to care for themselves and their sexual partners when the messages they receive about themselves are so negative.” The agency borrowed the ad from Seattle’s Northwest AIDS Foundation (today known as Lifelong AIDS Alliance), which created it in response to public health studies indicating that a gay man’s reducing his risk for HIV infection is directly correlated to his self-esteem and sense of self-worth. The ad aimed to break down negative stereotypes of gay men, and concluded with the message, “Ending AIDS begins with pride.”⁸⁹⁰

Like growing numbers of gay health professionals, Dana Van Gorder, then coordinator for lesbian and gay health services in the San Francisco Department of Public Health, believed that issues of well being should take precedence over technical information about HIV. He explained, “Gay men had major psychological issues before the epidemic came along, and the epidemic made it worse. So many gay men feel they live in isolation, and that they’ve lost their biological families

⁸⁸⁹. Larry Kessler, interview with author, Boston, 24 July 1995.

⁸⁹⁰. AIDS Action Committee of Massachusetts, “AIDS Action Launches New Statewide Initiative to Stem Tide of New Infections Among Gay Men” (News release, 19 June 1995).

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and support networks.”⁸⁹¹ Stacked against the pain of living, the risk of HIV infection—particularly at a time when new treatments were so promising—may have seemed for some a reasonable price to pay for a bit of intimacy with another person. But, Van Gorder, argued, if prevention education was going to work it first had to help gay men value and protect themselves in order to live and be well for a brighter, hopefully AIDS-free, future.

In a series of articles for the *San Francisco Sentinel*, Van Gorder in 1995 described how HIV prevention for gay men had become far more than a medical issue. “HIV prevention should no longer be thought of simply as the effort to keep gay and bisexual men free from HIV,” he wrote, “but as a movement to help them grow old, valued, and fulfilled.” The first step, he noted, “is an uncensored, community-wide discussion about all of the factors that challenge our ability to remain uninfected.”⁸⁹² Underscoring the interrelationship between gay men’s personal choices and their relationship to the community, Van Gorder told me, “Somehow the community has lost sight of the notion that it needs to provide for its future and for its survival. Some people have to be willing to stand up and say, fine, you get to make your choices—yet we also need to encourage you to make sure you make a good choice, an informed choice, and that you make the choice within an environment in which you are comfortable that you have come to the right conclusion.”⁸⁹³

⁸⁹¹. Dana Van Gorder, interview with author, San Francisco, 31 January 1995.

⁸⁹². Dana Van Gorder, “Prevention More than Medical Issue,” *San Francisco Sentinel* (11 January 1995), 20.

⁸⁹³. Van Gorder interview.

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In the earliest days of the epidemic, Donald Krintzman, the first person with AIDS ever to be interviewed in the press, recognized that the key to dealing with the AIDS epidemic just then beginning to break out among gay men was going to be the gay community's ability to pull together and keep everyone focused on a future free of AIDS. "If we embrace the community concept," said Krintzman, "if we can engage our collective intelligence, courage and maturity, our emphasis will be on the overcoming rather than on the suffering of this disease."⁸⁹⁴ Only two years after Krintzman's comments, *Washington Blade* editor Steve Martz in 1983 observed that the term "gay community" had already taken on new meaning because of the way gay people had responded to AIDS. Wrote Martz, "One can tell where a true sense of community exists by the way its members treat the weakest among them and by that yardstick, the compassion that gays are showing to those afflicted with AIDS is a wonderful sign of strength."⁸⁹⁵

From a historian's point of view, John D'Emilio observed in 1996, "For better or worse, the AIDS epidemic has helped to foster, at least among some of us, a sense of community in its fullness that we might not have felt before." He added that the widespread experience of sickness and death among gay men has "created an emotional level of connection that extends further for more people." The greatest challenge to gay individuals and the community as a whole, said D'Emilio, continued to be

⁸⁹⁴. Lawrence D. Mass, MD, *Homosexuality and Sexuality: Dialogues of the Sexual Revolution*, vol. 1 (New York: Harrington Park Press, 1990), 140.

⁸⁹⁵. Steve Martz, "A Concluding Word," *Washington Blade* (25 February 1983), 21. Quoted in Rodger Streitmatter, *Unspeakable: The Rise of the Gay and Lesbian Press in America* (Boston: Faber and Faber, 1996), 267.

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homophobia—which gay people still too often turned in upon themselves. “The fact that gay men are still seroconverting tells us something about the complexity of what sexuality is all about,” he said, “but also how we’ve underestimated the power and depth and insidiousness of homophobia. If our lives were easier, without the effects of our oppression and the ways we’ve internalized it, safer sex would be a lot easier to be integrated into our lives because the desire for sexual passion and intimacy and connection would not have this added layer of desperate meaning attached to it that the oppression creates.”⁸⁹⁶

Another challenge to the community’s ability to help gay men imagine healthy and long lives was, paradoxically, its very willingness to do its own prevention campaigns, care for those with the disease, and push for political attention and public financial resources to underwrite the costs of prevention and care. Laudable and necessary as those efforts have been, they have had the unwanted effect of linking gay people with the epidemic in a way that has made it difficult for many, gay and nongay alike, to separate gay identity from AIDS. Even the cultural outpouring inspired by AIDS resulted in once again linking homosexuality to a medical diagnosis—precisely what gay people, like Larry Mass, feared early in the epidemic.

The art created by gay people in the AIDS years unwittingly conveyed a sense that AIDS was their only concern. Not only was this grossly reductionist, it was harmful to the broader efforts of the gay civil rights movement to show gay people as multifaceted human beings—just like heterosexuals. Gay writer and GMHC cofounder Edmund White, living with HIV himself, disputed the view that AIDS was, as some argued, the only “le-

⁸⁹⁶. John D’Emilio, interview with author, Washington, DC, 24 May 1996.

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gitimate” subject for gay writers and artists. In 1994 he said, “Gays, even in their own eyes, get reduced to a single issue, which is after all a medical one. There is a kind of ‘remedicalization’ of homosexuality going on, which I find very dangerous.”⁸⁹⁷

Since the early seventies, the community has sought to counter the negative, even pathological, images of homosexuals by nongay people and gay people themselves who may be uncomfortable with their own sexual orientation. One way it has done so is in the creation of community institutions, places where people can share their lives with others like themselves and feel at home. For a community now suffering the twin plagues of homophobia and HIV, community institutions offered safety and solace. As Ginny Apuzzo put it, “We need institutions where people can bring the grief and the pain and the despair and find a way to relieve it.”⁸⁹⁸

One community institution that predated AIDS adapted to the community’s needs in the epidemic and now looks to a future beyond it. This is the Los Angeles Gay and Lesbian Center, the largest gay community organization anywhere. The center has played a pivotal role in nurturing gay people through the epidemic, and has, according to its director Lorri L. Jean, helped them imagine a healthy, even happy, future in spite of—and hopefully beyond—AIDS. “We live in a society that tells us from the day we’re born that there’s something wrong with gay and lesbian people,” said Jean, “and many buy it.” At the heart of the center’s programs, she told me, is an effort to build self-

⁸⁹⁷. Thomas Avena, “Interview: Edmund White.” In Thomas Avena, ed., *Life Sentences: Writers, Artists, and AIDS* (San Francisco: Mercury House, 1994), 226.

⁸⁹⁸. Apuzzo interview.

PART 10: VICTORY DEFERRED

esteem. She explained, "We try to show people that you can be gay or lesbian and 'out,' and you can lead happy and productive lives, that your future is not just one of sadness and discrimination and bigotry, but that we do have some power over changing our lives. Part of that is about hope. We try in all our programs to promote hope and self-esteem because if you feel good about yourself, even if you have HIV or AIDS, you [will believe that you] are unique and worth preserving."⁸⁹⁹

The important work of gay community institutions like the center notwithstanding, many gay men looked outside the community itself for a sense of connection and support that transcends sexual orientation. For Dana Van Gorder, in hard-hit San Francisco, it was a matter of interacting with heterosexual friends who, because they didn't live in the war zone he did, where so many young men have died, could remind him that life is for the living. "I had to look outside the community for support and to gain perspective," he told me. "When I talk to my straight friends in Los Palos, and they say 'are you staying safe?' there's an assumption on most [gay] people's part that that's homophobic, that they're meddling in my sexuality. The point is that they don't want to see you getting sick, they love you."⁹⁰⁰

Others, particularly gay men of color, found identity and support in their ties to families and communities to which they belong through race and ethnicity, religious faith, or culture. For Randy Miller, connection to the Black community provided a source of strength and perspective. While many gay men, particularly white men, leave their families for places like San

⁸⁹⁹. Lorri L. Jean, telephone interview with author, 26 October 1995.

⁹⁰⁰. Van Gorder interview.

VICTORY DEFERRED

Francisco, Miller pointed out that other “paradigms” are available. One paradigm, chosen by many gay men of color, is to stay in one’s community of origin and figure out how to live as an “out” gay person among family and childhood friends, drawing on the community’s sense of shared history and response to life’s vicissitudes. “As a Black gay man,” said Miller, “I draw on my community’s sense of history about dealing with slavery and oppression for hundreds of years in this country.” What this has meant, said Miller, is that although AIDS has been “a horrific thing,” it doesn’t rattle his sense of personal identity the way it did for many white gay men whose identities were bound up strongly in their sexual orientation. “It’s a horrific thing like many horrific things I have to survive,” he said.⁹⁰¹

For the Reverend Carl Bean, being connected to the broader world is not only important in coping with AIDS but in life generally. “It has never attracted me to be in a Castro or West Hollywood,” he told me. “I like talking to the old lady in my building in LA—she has a nephew who is gay. She’s a delight, a wonderful woman. I have a Russian couple who moved over here recently, and we talk. There’s gay folk in my building, and there’s Asian folk, Black folk, Jewish folk, Greek folk. To me, that’s humanity. Coming from a past of segregation, I don’t understand wanting to create segregation. How are we ever going to love, share, bring about these things that we say our country is built on if we’re afraid to know each other?”⁹⁰²

One gay institution that fosters a spirit of community among gay people doesn’t have the word “gay” in its name. San Fran-

⁹⁰¹. Randy Miller, interview with author, Washington, DC, 17 August 1995.

⁹⁰². Rev. Carl Bean, interview with author, Washington, DC, 16 November 1995.

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cisco's Café Flore has been drawing coffee drinkers and people watchers since 1974. NAMES Project founder Cleve Jones had been a regular for more than twenty years, and had been interviewed earlier in the day for a history of the café, when we talked in early 1995 about the always hopping coffee shop on the edge of the Castro district. Psychologist John Newmeyer described Café Flore as a community institution ideally suited to usher young gay men in particular into the gay community. He noted that comfortable, welcoming places like Café Flore are especially important when, as he and others expect, young men will continue to represent a leading edge of the ongoing AIDS epidemic in the United States. Newmeyer predicted in 1995 that upwards of 15 percent of young gay men in San Francisco alone would ultimately be infected.⁹⁰³

Clearly prevention aimed at young gay men must be a top priority for the gay community and the nation, and community institutions must welcome and support them. But what of the not-so-young gay men who continued to be a risk for HIV infection? AIDS advocates often spoke of the young men at risk, overlooking the fact that the emphasis among many gay men on the young, and youth in general, has been an important obstacle to the ability of older gay men to look to the future and embrace the idea of a healthy, long life. As Dana Van Gorder put it, "It is fairly clear gay men are experiencing a lot of problems 'growing up' and dealing with the transitions in their lives from sexually attractive men in their twenties, whom everybody is sort of after, to men in their thirties, forties, and early fifties,

⁹⁰³. John Newmeyer, interview with author, San Francisco, 31 January 1995.

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and feeling that they don't look quite as good anymore and can't quite figure out how to deal with that transition."⁹⁰⁴

In a 1996 *New York Times Magazine* essay called "The Wrinkle Room," author Andrew Holleran, whose despairing novel about a middle-aged gay man, *The Beauty of Men*, had just been published, lamented the passing of youth and voiced the uncertainties of being an "older" gay man in a youth-obsessed culture. "Wrinkles, of course, are not confined to gay men of a certain age," wrote Holleran. "Gay men's identity, however, is thought to be based, more than most people's, on being *unwrinkled*." He described a film star who, now old, was unrecognized as he emerged from a nightclub. He then described a gay friend who, at forty-five, was obsessed with being let into a popular night spot called Club USA "In this mindset," wrote Holleran, "the doorman at Club USA does become the Grim Reaper, and a certain estrangement ends up feeling like ostracism."⁹⁰⁵

Fortunately, not all older gay men concurred with Holleran's bleak assessment. In a follow-up letter to the editor, septuagenarian composer and writer Ned Rorem observed, "When Andrew Holleran, age fifty, defines gay men's identity as based, 'more than most people's on being unwrinkled,' where does that leave me, age seventy-two, and my contemporaneous gay friends? Like everyone, we sowed wild oats, but as the bloom faded, we readjusted our tempo and talents to the inevitable,

⁹⁰⁴. Sidney Brinkley, "AIDS Conference Focuses on Grassroots Issues," *Washington Blade* (29 March 1996), 17.

⁹⁰⁵. Andrew Holleran, "The Wrinkle Room," *New York Times Magazine* (1 September 1996), 60.

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and did so as individuals.”⁹⁰⁶ Many older gay men, particularly those who had suffered the losses of the AIDS years, also recognized the importance of being mentors and role models for younger men. Arnie Kantrowitz, about to turn fifty-six a week after our 1996 interview, found great satisfaction in helping young people avoid the terror of coming to grips with their homosexuality. Speaking of his own sense of isolation as a younger person, he said, “What a difference it could have made for me to have contact with someone.”⁹⁰⁷

Still other men responded to the existential issues raised by aging and loss through the time-honored means of parenting. Boston psychiatrist Marshall Forstein told me, “I come from a family that has always instilled in me how important connectedness is with the people who came before and will come after. I think where gay culture has suffered is in our unwillingness to see our connectedness over time.” He explained that his own decision to adopt a child, more than a decade earlier, grew out of a desire to leave a legacy in the world. “I’m not saying parenting is the answer to the question of generativity,” said Forstein, “but it’s the particular route where I have addressed my issues of what I’m contributing to the world, what I leave behind, and how I find a place in the marching on of time.” He added, “I think for so many years gay people lived in a world that said you are not acceptable the way you are, you are in-

⁹⁰⁶. Ned Rorem, letter to the editor, *New York Times Magazine* (22 September 1996).

⁹⁰⁷. Arnie Kantrowitz, telephone interview with author, 22 November 1996.

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trinsically defective. Well, with those internalized beliefs, why would you care about leaving something behind?"⁹⁰⁸

Torie Osborn believes there was a direct correlation between the AIDS epidemic and the seeming upswing in the nineties in the number of gay men raising children, what she called a "gayby boom." Said Osborn, "There's a huge transformation of values, a huge resurgence of spirituality and of connecting to kids. If I look at my friends across the country, gay and gay-identified, the people who are coping the best with the epidemic are the ones who have kids in their lives and straight people in their lives." Osborn offered the example of her HIV-positive male friend who decided to adopt a child. She recalled him saying, "I want to see life at the beginning. I think I will die sooner if I don't stop seeing life only at its end."⁹⁰⁹

Unfortunately, the efforts of gay Americans to enjoy the fullness of life remained limited by the homophobia of American politics that forces us to be second-class citizens. The support of same-sex marriage that people like Larry Mass called for in the earliest years of the epidemic as a means of channeling the sexual energy of gay men away from unsafe situations and into committed relationships was as ignored in the late nineties as it was in the early seventies. When President Clinton signed the so-called Defense of Marriage Act, in 1996, he claimed he did so merely to silence an "unpleasant debate" about whether gay people should have the legal right to wed and the same legal benefits that heterosexual couples take for granted.

⁹⁰⁸. Marshall Forstein, MD, interview with author, Washington, DC 13 September 1995.

⁹⁰⁹. Torie Osborn, interview with author, Washington, DC, 15 February 1995.

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If gay Americans thought we had somehow “proven” ourselves by responding with compassion and humanity in the AIDS epidemic, we were brutally reminded all over again of our outlaw status in American society as states raced to join the federal government in denying the equal rights of gay men and lesbians through measures to prevent the recognition of same-sex marriages. A Valentine’s Day 1997 issue of the *Washington Blade* reported that when Mississippi two days earlier became the seventeenth state to ban legal recognition of same-sex marriages, Republican Governor Kirk Fordice proclaimed, “For too long in this freedom-loving land, cultural subversives have engaged in trench warfare on traditional American values.” He added, “These radical subgroups have distorted the national agenda and defiled time-honored customs for their own selfish purposes. Today, the state of Mississippi takes a significant step to protect the foundation of a healthy society.”⁹¹⁰

As conservative politicians protected their fear- and hate-driven versions of a healthy society, gay people continued to create new ways to protect their lives. “Healthy people are more likely to make healthy choices,” observed University of Minnesota psychologist and sex educator Simon Rosser. “Rather than beating people over the head with a technological argument about needing to use a condom, we need to face the tougher question about how to build a healthy community because in the long term it’s going to be healthy people who will make a difference in the epidemic.”⁹¹¹ Gabriel Rotello in *Sexual Ecology* described this as “transformative change,” which, he said, involves “the integration of sexuality into the whole of life,

⁹¹⁰. Lisa Keen, “Mississippi Governor Signs Marriage Measure,” *Washington Blade* (14 February 1997), 1.

⁹¹¹. B. R. Simon Rosser, telephone interview with author, 14 August 1995.

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a life that respects sex but does not make it the central point of existence.”⁹¹²

Just as it launched nationwide trends in rock music and gourmet-coffee drinking, Seattle in the mid-nineties pioneered a new, integrated approach to prevention education for gay men that promised to revolutionize the field and revitalize the gay community by viewing prevention as a subsection of gay community-building. In 1996, a Seattle group called Gay City Health Project electrified an audience at the National Lesbian and Gay Health Conference, held in Seattle, with its vision for the health and well being of the gay community. The group’s director at the time, John Leonard, described Gay City’s vision this way: “Imagine no more poignant memorial services. No more ‘twenty-something and HIV-positive’ support groups. No more AIDS protests, no more AIDS fundraisers. And no more fucking red ribbons. Imagine a future of equality, diversity, community. Imagine a time when gay men count gray hairs and not T-cells. Imagine a world where we’re raised to love ourselves as healthy, whole, and beautiful. Imagine a place where holding hands is not an act of courage. And having sex is not against the law. Imagine no fear, no more grief. Imagine no more new HIV infections.”⁹¹³

From its beginning as a county health-department task force exploring prevention options for gay men, Leonard said, “Gay City wasn’t just about something bad that we wanted to prevent, but about something really good that we wanted to create.” The group’s mission, he explained, is “building com-

⁹¹². Gabriel Rotello, *Sexual Ecology* (New York: Dutton, 1997), 244.

⁹¹³. John Leonard, “Welcome to Gay City,” presentation at the National Lesbian and Gay Health Conference, 17 July 1996.

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munity, promoting communication, and nurturing a culture where gay men see their lives as worth living.” Drawing on well-established educational models, the group created its programs in response to what they heard from gay men. Said Leonard, “We were told to build community, build connections among gay men, build a greater sense of responsibility among men for each other, and help men feel better about being gay.”

In January 1994, Gay City held the first of a series of extremely well attended forums, “Why Are Fags Still Fucking Without Condoms?” Three hundred people attended. I asked Leonard how people reacted in the forum when men spoke up about their unsafe sexual experiences, a taboo subject among gay men who looked at prevention educators as authority figures. “I remember a collective sigh of relief that finally somebody was saying it,” he said. “I don’t think anybody was shocked because I think on some level we knew that we weren’t being good little boys all the time, but it wasn’t okay to talk about and people did and do feel a lot of stigma admitting that, especially if they’re HIV-positive.”

Hundreds more showed up at subsequent Gay City forums, each one dedicated to timely issues such as dating, oral sex, coming-out, relationships between HIV-positive and HIV-negative men, drug and alcohol use, and other topics of interest to gay people that don’t, at first blush, look like HIV prevention. More than seven hundred participated in a May 1996 forum on “charting our futures” featuring lesbian activist Urvashi Vaid. A forum on gay history the following month grew out of one young gay man’s standing up in an earlier program and saying, “I don’t know who Judy Garland was. Talk to me about pre-Stonewall. It would help me feel better about the gay community and other gay men to know a little about where I came from.”

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As Leonard explained, “We talk about how you need more than just condoms and practice putting them on a banana to practice [safer sex] over the long run. You need to address broader social issues, and those have to do with self-esteem, and feeling a part of a community that you feel connected to.” He said that gay men in Seattle responded very positively to Gay City’s positive vision. “In the surveys we do,” he told me, “people report that coming to forums, even if not directly about HIV prevention, has an impact on them that makes them leave the forums feeling more pride and connection to the gay community, and feeling greater motivation to practice safer sex and take care of their health.”⁹¹⁴

In 1998, similar programs were launched at the nation’s two oldest AIDS organizations, GMHC and the San Francisco AIDS Foundation. In a series of small workshops, GMHC’s new “Beyond 2000” program encouraged gay men to examine and discuss how their own sexual behavior fit in with their ideas about masculinity, sex, and drug and alcohol use. The AIDS Foundation’s new program, “Gay Life,” was intended to create a sense of community and build self-esteem. Rene Durazzo, the foundation’s deputy director of programs, said, “Gay Life was constructed in appreciation for the fact that men’s whole lives impact their sexual decision-making.” Based on a study by the University of California–San Francisco, and funded equally by the city and the foundation, the new program featured a major publicity campaign, forums, social events, one-on-one and couples counseling, and a “Black Brothers Esteem” group for African-American gay and bisexual men. Like Seattle’s Gay City, the foundation’s program included a series on gay culture and community history. More than anything, it recognized and affirmed the individual decisions gay men had been making

⁹¹⁴. John Leonard, telephone interview with author, 2 January 1997.

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throughout the epidemic. Said Durazzo, “It was important for us to step back and refocus and resituate ourselves in relationship to those decisions, to be less health educators and more facilitators and supporters of men finding safe places to self-reflect and sort through the decisions they want to make.”⁹¹⁵

The reinvention of HIV prevention not only marked an adjustment to the fact that gay men would continue to be affected profoundly, but it signaled a maturing, sophisticated community that was once again creating its own ways to survive and thrive even amidst the ongoing assaults of HIV and homophobia. Helping to make gay men aware of their history and invested in their community, and increasing their understanding of the political implications of their personal behavior, could only serve to strengthen the gay civil rights movement. At the same time, reinforcing the pride and self-esteem of individual gay men offered them the support they needed if they were to greet their “future worth living for” with open arms, strong hearts, and the desire to savor life’s sweetest pleasures after knowing too well and for too long its bitterest realities.

⁹¹⁵. Mark Mardon, “SFAF’s Gay Life: A New Route to Prevention,” *Bay Area Reporter* (30 April 1998), 1.

THIRTY-EIGHT

“People with AIDS are dying!” shouted the heckler from the 1,500-member black-tied, evening-gowned audience at the Grand Hyatt Hotel in Washington, DC “Sit down!” yelled others in the audience. They weren’t yelling at the speaker on stage but at the gay man among them who’d had the temerity to shout his rage. Was it Larry Kramer heckling Ronald Reagan’s first speech on AIDS in 1987? Hardly. This was an orgy of mutual admiration. “We love you, Bill!” erupted repeatedly from the crowd who’d paid hundreds to see and hear Bill Clinton become the first sitting president ever to address a gay rights group when he spoke on Saturday night, November 18, 1997, at a \$300,000 Human Rights Campaign fundraising dinner. Clinton once again warmed gay hearts—as he’d done in his first campaign, if rarely afterward—by quoting his predecessor Harry Truman’s speech to the NAACP fifty years earlier, vowing equality for all Americans. “And when I say all Americans,” Truman said, “I mean all Americans.” Clinton added, “Well, my friends, all Americans still means *all* Americans.”

With his trademark political panache, Clinton addressed—and dismissed—his heckler. “People with AIDS *are* dying,” he said. “But since I’ve become president, we’re spending ten times as much per fatality on people with AIDS as people with breast cancer or prostate cancer. And the drugs are being approved more quickly. And a lot of people are living normal lives.

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We just have to keep working on it.” The audience gave him one of many standing ovations.⁹¹⁶

Applause was the furthest thing from the minds of the Presidential Advisory Council on HIV/AIDS a month later when it issued a “progress report” that harshly condemned the Clinton administration’s efforts on AIDS. After beginning by saying that, yes, Clinton had been the first president “to take serious action to address the AIDS crisis,” the thirty-member council said the administration “has sometimes failed to exhibit the courage and political will needed to pursue public health strategies that are politically difficult but that have been shown to save lives.” In particular, said the group, federal prevention efforts were still ignoring recommendations to provide “frank, explicit, culturally relevant HIV prevention information to those at risk for sexual transmission.” Like the Reagan and Bush administrations, the council said the Clinton administration “has failed to lay out a coherent strategic plan of action.” The report noted that upcoming measures of the administration’s commitment on AIDS would include its proposed AIDS budget for 1999 and its actions on needle exchange as a prevention measure for the ever-growing number of injection drug users at risk for infection or infecting a needle-sharing partner.⁹¹⁷

The president’s proposed 1999 budget indeed offered increased funding for AIDS programs, a total of \$3.9 billion for AIDS research and services—a \$314 million increase over 1998. Of that amount, \$1.3 billion would go for the Ryan White

⁹¹⁶. Peter Baker, “Clinton Equates Gay Rights, Civil Rights,” *Washington Post* (9 November 1997), A18; Official White House transcript of the president’s keynote address.

⁹¹⁷. Peter Freiberg, “Commission: Federal AIDS Effort Stalled,” *Washington Blade* (12 December 1997), 1.

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CARE Act services, a 14 percent increase. Another \$385.5 million, a 35 percent increase, would be allocated for the AIDS Drug Assistance Program. The federal AIDS housing program would increase 10 percent, from \$204 million to \$225 million. And the National Institutes of Health would receive an additional \$124 million for AIDS research, bringing its share of the AIDS budget to \$1.731 billion. As for HIV prevention, Clinton proposed to increase the CDC's HIV prevention budget by \$5 million, for a total of \$637 million. In actual fact, the increase wasn't even for AIDS prevention per se but for a special program aimed at curtailing inequities in health care for minority communities. Nevertheless, Clinton's AIDS policy advisor, AIDS "czar" Sandra Thurman said, "This is a statement by the president that the resolve to ending this terrible epidemic remains firm."⁹¹⁸

The firmness of the president's resolve was called seriously into question only two months later when Clinton stunned Thurman, his secretary of Health and Human Services, his own HIV/AIDS council, AIDS advocates, and scientists alike when he unexpectedly announced on April 20 that, despite scientific evidence that needle exchange programs help to curb the spread of HIV among drug users, federal funding could not be used to support such programs. Although Health and Human Services Secretary Donna E. Shalala, like most of the administration's senior health officials, had argued that funding needle-exchange programs made sense, Clinton's political heart went with Barry R. McCaffrey, the retired general who headed the Office of National Drug Control Policy. McCaffrey persuaded Clinton that funding needle-exchange programs would open the administration to criticism that it was "soft on drugs." So Clinton declared that—despite findings from the National Institutes of

⁹¹⁸. Lou Chibbaro, Jr., "AIDS Funding Gets a Boost," *Washington Blade* (6 February 1998), 1.

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Health that the programs were effective in reducing the spread of HIV, and despite the endorsement of the AMA and the National Academy of Sciences—they would have to get along without the federal government’s support.⁹¹⁹ Dr. R. Scott Hitt, the openly gay physician who chaired the president’s HIV/AIDS council, said, “At best this is hypocrisy. At worst, it’s a lie. And no matter what, it’s immoral.”⁹²⁰ The *New York Times* said, “Instead of making a principled decision, President Clinton is fecklessly trying to appease conservatives with a policy that will cost thousands of lives.”⁹²¹

Some things never really seem to change in America, no matter which politician occupies the Oval Office. Ironically, just a year before Clinton had challenged the American scientific community to make an AIDS vaccine its “first great triumph of the twenty-first century.”⁹²² As it had done since Reagan was president, politics once again trumped science when it came to preventing the further spread of HIV, if it meant upsetting conservative moralists.

As federal HIV prevention efforts remained captive to politics and gay politicians patted one another on the back for landing the president at their exclusive dinner, ordinary gay people were as hated and persecuted as ever. The number of gay men

⁹¹⁹. John F. Harris and Amy Goldstein, “Puncturing an AIDS Initiative,” *Washington Post* (23 April 1998), A1.

⁹²⁰. Sheryl Gay Stolberg, “President Decides Against Needle Programs,” *New York Times* (21 April 1998), 1.

⁹²¹. Unsigned editorial, “Cowardice on Clean Needles,” *New York Times* (22 April 1998), A30.

⁹²². John F. Harris, “Clinton Appeals to Science for an AIDS Vaccine,” *Washington Post* (19 May 1997), A7.

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and lesbians discharged from the military was higher than ever under Clinton's "Don't Ask, Don't Tell" policy, which the president had intended to allow gay members to serve so long as they "kept quiet" about their sexual orientation.⁹²³ Nineteen states still had laws against sodomy, selectively enforced against gay men.⁹²⁴ A study of high school students found that more than one-third of them had "missed school because of fear for their safety" in the previous thirty days.⁹²⁵

Another study found that while middle-class Americans prided themselves on their nonjudgmentalism, they didn't hesitate to call gay people "sick," "perverted," and "mentally ill." An August 1998 *Newsweek* poll found that while most nongay Americans said gay people deserved equal rights in housing and jobs (83 percent and 75 percent, respectively), 54 percent believed homosexuality was a "sin."⁹²⁶

As the president of the United States answered questions from a grand jury about his own sexual behavior, the radical right exploited Americans' ambivalence about homosexuality to inject their particular brand of poison into the national debate. Never ones to miss a chance to show that behind their so-called "Christian love" was a frightening, even fascistic, level of fear-driven hate, a coalition of conservative groups—including

⁹²³. Tim Weiner, "Military Discharges of Homosexuals Soar," *New York Times* (7 April 1998), A24.

⁹²⁴. Paul Duggan, "Texas Sodomy Arrest Opens Legal Battle for Gay Activists," *Washington Post* (29 November 1998), A3.

⁹²⁵. Peter Frieberg, "Study Verifies Teen Suicide Data," *Washington Blade* (8 May 1998), 1.

⁹²⁶. Marc Peyser, "Battling Backlash," *Newsweek* (17 August 1998), 50–52.

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the Christian Coalition and the Family Research Council—launched a high-profile campaign in the summer of 1998 aimed at portraying gay people as sick perverts who could be “healed” through prayer and counseling. Hoping to pressure Republicans to toe their line as the November elections approached, the group sponsored newspaper ads quoting none other than the Senate majority leader, Trent Lott (R-Mississippi), who in June had likened gay people to alcoholics and kleptomaniacs.⁹²⁷

Across the country, the *Washington Blade* reported, “Gays are on the defense in matters of marriage and family issues, and on the offense in trying to secure basic protections against discrimination and violence.” Despite a drop in serious crimes across the country, reported incidents of hate crimes based on sexual orientation actually rose 8 percent from 1996 to 1997, according to the FBI.⁹²⁸

In the rarefied air of the Human Rights Campaign’s offices, things didn’t seem that bleak. Heady from a sense of “power” from their evening with the president, HRC announced in early 1998 that, together with the Metropolitan Community Churches, they would sponsor a fourth national gay civil rights march on Washington in the spring of 2000. Shirking the consensus-building among gay community organizations that had gone into planning the three previous national marches, the “Millennium March on Washington for Equal Rights” was viewed by

⁹²⁷. Hanna Rosin, Thomas, B. Edsall, “Religious Right Targets Homosexuality,” *Washington Post* (15 July 1998), 1.

⁹²⁸. First quote is from M. Jane Taylor, “An Ever-Shifting Landscape,” *Washington Blade* (13 February 1998), 1; second quote is from Peter Freiberg, “Gay Hate Crimes Rise 8 Percent,” *Washington Blade* (4 December 1998), 14.

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many national gay and lesbian activists as a power grab by HRC director Elizabeth Birch, a ploy to increase HRC's membership toward Birch's stated goal of one million members by 2000. Words like "self-aggrandizing" were used as often as "effective" in describing Birch, and her own words at times seemed to betray her—as in a 1998 profile in *Out*, which quoted her as saying, "Imagine what you would have done if three years ago you woke up and found that someone had handed you the movement."⁹²⁹ But most gay activists, who for years had lamented their lack of a charismatic individual to focus and lead the gay civil rights movement—as Martin Luther King, Jr., had done for African-Americans—weren't quite as ready to anoint Birch as she herself seemed to be. Just as AIDS service organizations did with their arguments about the "needs" of people with AIDS, Birch sometimes conflated her organization's interests with those of "all" gay people.

Robin Tyler, a lesbian comedian and events promoter hired by HRC and MCC to "produce" the Millennium March, asserted that HRC enjoyed the support of the "overwhelming majority" of gay people in the U.S. Although no one has ever produced a reliable measure of the number of gay people in this country, it seems reasonable to say there are many more than the two hundred thousand—mostly white, more-affluent-than-not—who made up HRC's membership at the time it announced plans for the march. Nevertheless, said Tyler, "If there's anything we've learned from the nineties it's that the majority of this movement is mainstream. You can't deny this and there's nothing wrong with this."⁹³⁰

⁹²⁹. J. Jennings Moss, "Capitol Gains," *Out* (April 1998), 112.

⁹³⁰. Lou Chibbaro, Jr., "Plans for March Unveiled," *Washington Blade* (6 February 1998), 1.

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Gay people were certainly brought further into the mainstream of American popular culture in the nineties, even if they were still reviled, discharged, arrested for having sex, and otherwise treated like strangers in their own homeland. “Lesbian and gay figures are becoming commonplace in mainstream media,” wrote gay reporter David W. Dunlap in a 1996 *New York Times* article. “And established institutions are growing less timid in courting gay and lesbian audiences.” Dunlap added that capitalism—the power of the almighty American dollar and the chance to tap into the alleged affluence of gay Americans—was a likely explanation for this growing interest in the gay “market.”⁹³¹

Not everyone welcomed the increasing “assimilation” of gay people. In the purplest prose and most sweeping of generalizations, Daniel Harris lamented in *The Rise and Fall of Gay Culture* that acceptance of gay people into the American mainstream meant the loss of an “ethnic” subculture as bitchy camp humor and the sense of always being an “outsider” gave way to what he saw as the bourgeois banality that characterized the mainstream. “The end of oppression,” wrote Harris, “necessitates the end of the gay sensibility.”⁹³²

Indeed, change was afoot. Even the stodgy *New York Times* had finally begun referring to homosexuals as “gay.” Movie studios were producing more gay-themed movies than ever, even if they were still serving up gay stereotypes. Gay New York City police officers in 1996 marched for the first time in the city’s gay pride parade, nearly three decades after the police raided the

⁹³¹. David W. Dunlap, “Gay Images, Once Kept Out, Are Out Big Time,” *New York Times* (21 January 1996), 29.

⁹³². Daniel Harris, *The Rise and Fall of Gay Culture* (New York: Hyperion, 1997), 270.

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Stonewall Inn and set off a more active and visible gay civil rights movement.⁹³³ Arch-nemesis of the seventies Anita Bryant was now selling copies of her gospel-music cassette, “I Am What I Am” in the lobby of her Anita Bryant Theater, in Branson, Missouri. When she wrote the song, Bryant said, she had never heard Jerry Herman’s song of the same name—the defiant showstopper sung by a drag queen in the musical *La Cage aux Folles*.⁹³⁴ In 1997, then-closeted lesbian comedian Ellen DeGeneres came out on her show *Ellen* and the mainstream media couldn’t get enough of the spectacle. The gay media that year lost a pioneering voice, the community’s earliest source of information about AIDS, which had later lost all credibility by championing the most outlandish explanations of the disease, when the *New York Native* ceased publication.⁹³⁵

In 1998, gay people were still on America’s mind—and even stirred Americans’ hearts. When Wyoming college student Matthew Wayne Shepard was savagely beaten and left tied to a rail fence to die alone on a cold October night, front-page

⁹³³. Charlie LeDuff, “At Parade, Proud Mix of the Blue and the Gay,” *New York Times* (30 June 1996), 27.

⁹³⁴. David Richards, “Anita Bryant, Reconstituted,” *Washington Post* (12 May 1996), F1. A generation after Bryant’s “Save Our Children” campaign succeeded in removing sexual orientation from the Dade County (Florida) human rights law, the Miami-Dade County Commission voted seven to six to reinstate it on December 1, 1998. Eleven states, twenty-seven counties, and 136 cities by this point, had laws protecting gay people against discrimination (see the unsigned [lead] editorial, “A Close Vote on Gay Rights,” *New York Times* 3 December 1998, A30).

⁹³⁵. Brian O’Connell, “*Native* Stops Publishing After 16 Years,” *Washington Blade* (17 January 1997), 14.

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news headlines, outraged gay people, clergy, and even elected officials joined their voices in denouncing the violence against gay people. The *New York Times* editorialized on 17 October, the day of Shepard's funeral, "It is a murder that seems to have aroused the deepest sympathies of the nation, a case in which law, religion, love, dignity and politics all seem on the side of a dead young man. It is a rare moment, and politicians and preachers had better take a lesson."

In such a state of flux, perhaps it was natural that disagreement erupted once again among urban gay men about what it "means" to be gay. In arguments that harkened back to the seventies, a handful of gay academics and porn stars calling themselves "SexPanic!" claimed—like John Rechy's "sexual outlaw" of the 1960s—that promiscuity is the essence of gay culture. One SexPanic! member, Rutgers University English professor Michael Warner, said, "It is an absurd fantasy to expect gay men to live without a sexual culture when we have almost nothing else that brings us together."⁹³⁶

On the other side were prominent gay writers including Gabriel Rotello, Michelangelo Signorile, and Larry Kramer, demonized by SexPanic! as "neo-conservatives." In an op-ed article in the *New York Times*, Kramer wrote, "Promiscuous gay men must hear the message, 'Enough already! Haven't you learned anything from the last seventeen years?'" He added, "Fortunately, more and more gay people are beginning to realize that it's time to redefine what it means to be gay. Allowing sex-centrism to remain the sole definition of homosexuality is now coming to be seen as the greatest act of self-

⁹³⁶. Sheryl Gay Stolberg, "Gay Culture Weighs Sense and Sexuality," *New York Times* (23 November 1997), 4-1.

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destruction.”⁹³⁷ Kramer’s commonsense message was the same as it had been in *Faggots*—and he was still being reviled for it.

If Rip Van Winkle had fallen asleep in 1978, when *Faggots* was published and Kramer was vilified for daring to challenge the gay “norm” of promiscuity, and had then awakened to the arguments of SexPanic! twenty years later, he could have easily overlooked the fact that hundreds of thousands of gay men had died horrific deaths because of a sexually transmitted disease. On the eve of the AIDS epidemic, Edmund White, a forbear of SexPanic!, said that for gay men at that point there were “few ways besides sex to feel connected with one another.” Without knowing how prophetic his words would be, White added that “in the future there might be surer modes for achieving a sense of community.”⁹³⁸

Nothing was surer than the devastation of the AIDS epidemic.

Not only did SexPanic! flout the epidemiologic facts of AIDS, but it ignored the fact that gay men because of the epidemic shared so much more than a priapic brotherhood of sexual rebellion insisting on a dubious “right” to promiscuity. Despite the many ways that gay people across the United States banded together to care for their own, and to preserve the memories of the community’s terrors and triumphs, some continued to question the legitimacy of describing the nation’s millions of gay men and lesbians as a genuine “community.” But as overused a

⁹³⁷. Larry Kramer, “Gay Culture Redefined,” *New York Times* (12 December 1997), A39.

⁹³⁸. Edmund White, *States of Desire: Travels in Gay America* (New York: E.P. Dutton, 1980), 260.

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term as it has become by its application to groups of people who share even the vaguest of commonalities, gay people could indeed consider themselves a community by virtue of their sharing a profound experience and responding together to address it.

In *Habits of the Heart*, sociologist Robert N. Bellah and his colleagues observed that genuine communities are such because they share a past and look together to the future. “For this reason,” note the authors, “We can speak of a real community as a ‘community of memory,’ one that does not forget its past.” In order not to forget that past, they said, a community continually retells its story, “its constitutive narrative,” offering examples of the men and women who have embodied and exemplified the meaning of the community. Besides tying us to the past by reminding us of our shared history, they said, genuine communities “turn us toward the future as communities of hope.”⁹³⁹

In the mid-nineties, I asked five individuals who played pivotal roles in gay America’s response to AIDS to reflect on the hard work and terrible cost of becoming a *genuine* community, a community of memory and hope. Cleve Jones, who marched with Harvey Milk and created the AIDS Memorial Quilt, said simply, “I think what we did mattered and I think we did the right thing. Even with all the mistakes, stupidity, and suffering, I’m still proud of it.”⁹⁴⁰ Rodger McFarlane, whose personal phone line became the hotline that was the first AIDS service ever of-

⁹³⁹. Robert N. Bellah, et al., *Habits of the Heart: Individualism and Commitment in American Life* (Berkeley: University of California Press, 1985), 153.

⁹⁴⁰. Cleve Jones, interview with author, San Francisco, 2 February 1995.

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ferred in the world, said, “Most people don’t have a sense of their own power. They don’t realize that one queen stepping outside a hospital administrator job and doing something different can make history.” He added, “We made history and changed the lives of millions of people just by stepping out from our own roles.”⁹⁴¹ Speaking of the AIDS services created and provided by the gay community, National Minority AIDS Council director Paul Kawata said, “I think the infrastructure that we built as gay men while we lost what we lost was extraordinary, heroic, unfathomable—and our legacy.”⁹⁴²

Ginny Apuzzo, who told Congress in 1983 that the government’s \$14.5 total AIDS budget should be increased to \$100 million, offered her own political vision in describing the political implications of the gay community’s experience with AIDS. “In this country, this movement will prevail,” she said. “If we hang in there, where civil rights and human rights are concerned across the board, and go for the generic issue of oppression, then we can make a difference, and we will prevail, and we will make the country a better place. I think that we are this country’s last, best hope because no other group has representatives in every corner of the oppressed world in this country. We cross every line.”⁹⁴³

Gay people would continue to fill important roles in addressing the epidemic as it surged on into the new millennium. In the broader arena of social and cultural life, we would witness in

⁹⁴¹. Rodger McFarlane, interview with author, New York City, 4 March 1995.

⁹⁴². Paul Akio Kawata, interview with author, Washington, DC, 24 March 1995.

⁹⁴³. Apuzzo interview.

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our words and deeds to the losses and the possibilities that constituted our experience of the AIDS epidemic. To accomplish this, a clarity of vision and certainty of purpose would be the important second steps, behind the willingness to serve. "It's a war," said Reggie Williams. "It is a fucking war, and it has affected so many people's lives, taken so many precious, beautiful, talented people away from us." As painful as it was for himself personally, living with AIDS and losing so many friends, "the reality is it *is*," said Williams. "And we've got to keep at it, we can't stop. When someone stops, someone has to pick up that sword and keep pressing on. Pick up the sword and keep fighting this battle to the bitter, fucking end, until it is out of our lives forever."⁹⁴⁴

Remembering the past would be essential to the "future worth living for" that HIV prevention educators said gay men must imagine and work toward if they were to sustain themselves individually and the community in general to confront the ongoing plague while getting on with life. To preserve the collective memory of the epidemic and its effects, novelist Fenton Johnson said a "genuine" gay culture needed to emerge. Because one of the principal acts of culture is devising means of passing along wisdom, Johnson said, "It will be interesting to see whether ten years from now we have figured out ways of passing on what we have learned, or if in fact we have sunk into the general morass of materialism and consumer society and forgotten what we have learned out of this experience." Johnson noted that gay survivors of the epidemic have an opportunity and obligation to share the wisdom gained from their experience, in the hope that others may learn, too. "Fortunately, HIV is a passing phenomenon," he said. "But we have to preserve and remember what there is to learn from the passing

⁹⁴⁴. Reggie Williams, telephone interview with author, 25 August 1995.

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phenomenon—just as the Jews are not engaged in the Holocaust now, but try actively to preserve its memory because of what it taught them, and what it can teach culture as a whole.”⁹⁴⁵

Although AIDS is obviously not only a disease of gay men, preserving the painful “heritage” of the AIDS epidemic requires that the gay community claim it in a certain sense as a “gay disease,” in that it has affected—and still affects, disproportionately—so many gay men, even as it affects others. Ben Schatz observed that many in the gay community tried so hard to be inclusive that they excluded gay men, which actually hampered efforts to get proportionate prevention funding. He drew an analogy to the experience of Jewish people and the Holocaust to illustrate how gay people could claim the uniqueness of their experience while respecting that of others. “Jews were not the only people who suffered in the Holocaust who need to be recognized,” said Schatz. “Yet the Jewish community has never been hesitant to speak about the special situation of the Jewish community.”

Gay people were reluctant to make any claim that they were treated differently, suffering in a particular way. “But,” said Schatz, “the whole government response has been fashioned by homophobia.” When Schatz first raised the issue, in the late eighties, gay people—eager to “de-gay” the epidemic—resisted. But he persisted. “As long as you convey the message that we are unimportant and trivial,” he told them, “you are enhanc-

⁹⁴⁵. Fenton Johnson, interview with author, San Francisco, 31 January 1995.

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ing the disease that is causing the symptoms we are suffering.”⁹⁴⁶

Arnie Kantrowitz told me that learning about the Holocaust—“carry[ing] that torch forever”—is his “way of being a Jew.” He explained, “I got fascinated by human behavior in the extreme. And the concentration camps were that. For us, the epidemic was that, too.” Although he doesn’t subscribe to a theory that the AIDS epidemic was purposely unleashed for political purposes, like the Nazi Holocaust, Kantrowitz pointed out a number of parallels between the experiences of Jews during the Holocaust and those of gay men in the AIDS epidemic. “The effects on us were quite similar,” he said, “being ostracized from others, in this case because they thought we were all infectious. You’d go to somebody’s house and see that they were nervous seeing you drink out of a glass. Or parents pulling their kids out of school. It was a terrifying time.”

When right-wing extremists demonized gay men in the mid-eighties, Kantrowitz helped to found the Gay and Lesbian Alliance Against Defamation (GLAAD) to counter the sometimes hysterical and fear-mongering portrayals of gay men in the news media. “As somebody who was so steeped in the Holocaust,” he told me, “I felt tremors going on, like the same thing was about to happen. It’s part of human psychology that it’s very hard to hurt someone like yourself, so you have to make them a ‘thing.’ The Nazis went far with that, where they called trains full of people shipments ‘of units.’ They dehumanized them to a level where they talked about people as though they were countable stock. It was a very effective device and ready to be used again by anyone.” People familiar with concentration camps did not take talk of quarantine lightly. “I was terrified and

⁹⁴⁶. Benjamin Schatz, interview with author, San Francisco, 2 February 1995.

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so were a lot of people,” Kantrowitz recalled. When GLAAD called its first meeting, 500 people showed up. “That shows you that the mood of fear was widespread,” said Kantrowitz, “not just that the epidemic would kill us but that our neighbors would run rampant, tattoo us, and isolate us.”⁹⁴⁷

Besides the memory of terror and fear, Kantrowitz said that a powerful legacy of wisdom and hope emerged from the devastation. In “Friends Gone with the Wind,” he quotes a man named Filip Müller, one of the inmates who emptied the gas chambers at Auschwitz, who described in the movie *Shoah* what he saw and learned from his horrific experience: “With our own eyes, we could truly fathom what it means to be a human being,” said Müller. “There they came, men, women, children, all innocent. They suddenly vanished, and the world said nothing! We felt abandoned. By the world, by humanity. But the situation taught us fully what the possibility of survival meant. For we could gauge the infinite value of human life. And we were convinced that hope lingers in man as long as he lives.”⁹⁴⁸

It would remain a challenge to get nongay people to look at and learn from the experiences of gay men in the AIDS epidemic when heterosexuals, white American men in particular, typically have little if any understanding of the experience of being the oppressed and marginalized “other.” The profoundly human experiences of gay people in the AIDS epidemic too often have been brushed aside simply by viewing gay people as “them” and not part of “us.”

⁹⁴⁷. Kantrowitz interview.

⁹⁴⁸. Arnie Kantrowitz, “Friends Gone with the Wind.” In John Preston, ed., *Personal Dispatches: Writers Confront AIDS* (New York: St. Martin’s Press, 1988), 24–25.

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Fenton Johnson described his own frustrating, embittering experience of speaking to a straight, educated, white man about his privileged place in the world, and realizing the man's complete obliviousness even as he complained of being discriminated against as a straight white man. Said Johnson, "This would be laughable if he weren't serious." Resisting the desire to either laugh or punch the man, Johnson realized this challenge was "to figure out some way to reach this person, enlightening him to the enormous grace that he has been given by virtue of his position in the universe so that he might realize how big the gift is that he has been given and how little he has done to deserve it."⁹⁴⁹

Lessons learned from the AIDS epidemic transcend the already artificial boundaries between homosexuals and heterosexuals, because they go to the heart of what it means to be human. But as with "coming out" as a gay person, the challenge for the epidemic's survivors would be to live as witnesses to the horrors they experienced and the changes they have wrought in individuals and the community. Bruce Patterson, the former GMHC hotline director and now a therapist, told me, "You can't go through something like that without feeling a profound change going on inside. It's given us a perspective beyond our years."⁹⁵⁰

In the AIDS years, young gay men often found deeply human connections with considerably older people because of striking parallels in their experiences. In "A Woman of a Certain Age," John Preston described a Yankee matriarch in Portland, Maine, named Franny Peabody. In the twilight years of a long

⁹⁴⁹. Johnson interview.

⁹⁵⁰. Bruce Patterson, interview with author, New York City, 2 March 1995.

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life, the Republican, Episcopalian shoe-factory owner was now a Democratic, Unitarian AIDS activist. Her grandson, Peter, died of AIDS early in the epidemic, and ninety-year-old Franny was determined to do everything in her power to help end for others the loneliness and social ostracism her own family experienced because of the disease. Over lunch with Preston, who hadn't told Franny of his own AIDS diagnosis, the pillar of Portland society described what she had learned from the gay men with AIDS she had known through her volunteer work on behalf of the AIDS Project of Southern Maine.

"Franny is seldom very emotional," wrote Preston. "She is, after all, a Yankee matriarch." But once, during lunch, there were tears in Franny's eyes. "My dear, it's so horrible," she said. "All my friends have died as well." Seeing that Preston was puzzled, Franny explained, "You see, my dear, all the people I know now are the children—sometimes the grandchildren—of the people I knew when I was young. The ones who are my own age are gone. I'm left calling sixty-year-old women 'girls,' and I sit and feel so alone some times. This is what you must be feeling." For her part, Franny said, "At least I am no longer frightened of death."

Taking Preston's hand, she continued, "That's the one thing you young men have given me. You have shown me that one can die with dignity and with courage. I was so petrified of death, it was so frightening, but now I understand that death comes, that one can greet it with a sense of propriety. I've sat with so many men and watched life leave them. So many, and they were all so brave. You will be, too. You already are." The

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two sat quietly a moment. Then Franny sat up, smiled, and said, “And now, my dear, how about a cocktail?”⁹⁵¹

Like Franny Peabody, gay men in the AIDS epidemic learned to cope with the reality of death while getting on with the business of living. As a result of working with AIDS professionally and as a volunteer, and dealing on a personal level with the illness and deaths of so many friends, Bruce Patterson said, “AIDS has given me a new appreciation for life.” At the “advanced age” of forty-one, Patterson said he was celebrating life by going out dancing once or twice a month. “That part of living, that joyous abandon is really something I don’t take for granted anymore,” he said.⁹⁵² After years of mourning, many gay men, like Patterson, were rediscovering “the crazy compulsion with which we resolved all the tangled impulses of our lives—the need to dance,” as Andrew Holleran put it in *Dancer from the Dance*.⁹⁵³

Boston psychologist Steven Schwartzberg likened the lives of gay men in the face of AIDS to the experience of driving past a grisly bus accident. “It looks terrible and awful,” he said, “But then you remember there’s dry cleaning to pick up.” He added, “We need to remember that we are living with an ever-present

⁹⁵¹. John Preston (Michael Lowenthal, ed.), *Winter’s Light: Reflections of a Yankee Queer* (Hanover, NH: University Press of New England, 1995), 115–24.

⁹⁵². Patterson interview.

⁹⁵³. Andrew Holleran, *Dancer from the Dance* (New York: William Morrow, 1978), 42.

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bus accident—and we still need to pick up the dry cleaning.”⁹⁵⁴ Approaching the third decade of the epidemic, Eric Rofes said the fact of the ongoing epidemic and the need to look to a brighter future required a challenging psychological balancing act. “We need to accept the fact that AIDS has happened,” he told me. “It’s not about accepting that there might not be a cure in our lifetime, but it’s about psychologically accepting the fact that AIDS has happened, accepting that people are dead and we’re never seeing them again, accepting that we’re going to be burying friends and lovers the rest of our lives, accepting the fact that our sexual lives have changed, accepting the way that in politics and the public image the linkage of homosexuality and disease and death are going to be there for many generations.”⁹⁵⁵

When gay people come out of our closets and let nongay people know and love us for our true selves, when gay people stand up and insist without apology that our losses and heroism in the AIDS epidemic be counted—as they should be—among the greatest of human tribulations and accomplishments, and when nongay people finally acknowledge the full and shared humanity of gay people, the true magnitude of the AIDS plague in this country will be understood.

At an ACT UP rally in Albany, New York, on May 7, 1988, film historian Vito Russo, who died from AIDS in 1990, put it like this: “Remember that some day the AIDS crisis will be over. And when that day has come and gone there will be people alive on this earth: gay people and straight people, Black people and white people, men and women—who will hear the story

⁹⁵⁴. Steven Schwartzberg, telephone interview with author, 22 June 1995.

⁹⁵⁵. Rofes interview.

VICTORY DEFERRED

that once there was a terrible disease, and that a brave group of people stood up and fought and in some cases died so that others might live and be free. I'm proud to be out here today with the people I love, and see the faces of those heroes who are fighting this war, and to be a part of that fight."⁹⁵⁶

Until the day when the deferral of victory over AIDS finally yields to a victory celebration of the most joyous magnitude, when gay Americans are accorded every right and dignity that *all* people are meant to enjoy, life for gay people in this country will continue to be a delicate balancing act between the future and past, hope and memory.

When Arnie Kantrowitz described his own life in the mid-nineties, years after the giddiness and promise of the seventies and several lifetimes' worth of experience later, he talked about how the AIDS epidemic reshaped his world, particularly because of the losses of Vito Russo and Jim Owles, his two best friends from their days together in Gay Activists Alliance in the early seventies. "There's some part of me that has never been able to deal with a certain level of it," Kantrowitz told me. "It's as if I just quietly had to accept that major pieces of my life were ripped out, and I had to keep walking, with no choice." Kantrowitz keeps a huge picture of Russo in his living room, and a photo of Owles on his desk. He wears the gold lambda ring GAA gave to Owles after his first year as president, the one Owles on his deathbed asked him to wear because he had been Owles' vice president.

For Kantrowitz, AIDS changed even the physical landscape of New York City, creating what he calls "hot spots." He explained, "I don't go near the block where Vito lived. I don't go

⁹⁵⁶. Quoted in Larry Kramer, *Reports from the holocaust* (New York: St. Martin's Press, 1989), 277.

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near the block where Jim lived. I once walked past Jim's house, and it's very strong, like this magnetic, intense feeling. I get it each time I walk past the hospital where he died." Greenwich Village—like the Castro in San Francisco, Dupont Circle in DC, "Boys Town" in Chicago, the South End in Boston, and so many gay neighborhoods across the country—with its promise of liberation, became a kind of ghost town haunted by the spirits of departed friends and painful memories. "Now when I walk around the Village," said Kantrowitz, "I'm constantly seeing the spot where I last said goodbye to this one, the window where so-and-so used to live, the street where that one lived and this or that event went on."

In 1996, the year that combination therapy offered the first real hope of finally being able to live with HIV rather than die an inevitable, terrible death from AIDS, Kantrowitz said it had gotten better, but not much. "I still know some people who are HIV-positive or even AIDS diagnosed," he said, "but no one I know is expected to die in the next year. So I think I've relaxed about it on one level." But on another level, he added, "I'm still in pain talking about it. I still light candles for my dead friends. I do my own rituals. I keep in contact with friends of friends. And I still cry."⁹⁵⁷

⁹⁵⁷. Kantrowitz interview.

PART 11

THE PLAGUE CONTINUES

*I learned that courage was not the absence of fear,
but the triumph over it.
The brave man is not he who does not feel afraid,
but he who conquers that fear.*

NELSON MANDELA

Thirty years since American gay men began to die from AIDS, effective but expensive and toxic treatment has rendered infection with the virus that causes the fatal illness as close to a chronic, manageable condition as it has ever been. Relieved after years of disease, death, and the threat of infection hanging over every intimate encounter, many privately insured middle-class gay men—including those living with HIV—moved on. Talk among activists has grown more excited about finding a cure for HIV. But even a cure will be of limited benefit when half of those infected with the virus don't know their HIV status. Even in San Francisco, the epicenter of AIDS in gay America, most people who test HIV-positive don't realize they are infected because they have no symptoms.

Today the national gay political organizations, once the most outspoken champions of gay men at risk for HIV, are consumed

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with fighting for the right to “marriage equality.” In their view, the HIV-focused organizations are “taking care of” the politics of the epidemic. But those organizations stopped advocating for gay men back in the 1980s, when they realized women and children were less “controversial” than standing up for the gay and bisexual men most in need of advocacy because most widely affected.

With no one looking out for gay and bisexual men, especially men of color, and with the pernicious 1987 Helms amendment still blocking federal funding for realistic prevention programs, taxpayer dollars intended for HIV prevention continue to be squandered on general information campaigns rather than paying for targeted, explicit campaigns aimed at those who most need them. Prevention educators continue to puzzle over how best to reach both young and not-so-young men with messages of hope and healing that are desperately needed by people who experience appalling cruelty and hatred at the hands of peers, too often parents, and American society at large. Meanwhile, recent research into gay men’s love lives is yielding fascinating new ways to tailor HIV prevention strategies based on an individual’s personal information.

The deadly silence resounds across gay America, from New York to San Francisco, in bedrooms and in boardrooms where the leaders of gay and lesbian organizations meet to discuss their priorities, which always seem to leave out HIV. Young gay men don’t want to hear about the struggle and suffering of their community in the darkest years of the plague. Older men, survivors, likewise don’t want to talk about it, instead withdrawing from the gay community after years of grief and rage.

As a fourth decade of AIDS begins, the challenge remains to transmute our losses and victories in the AIDS years into an inspiring story of love in action. As always, it will be up to each

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of us to draw the strength we need from our individual and collective resilience. Spanning the generations of age and experience, mentors can help teach their younger protégés to tap their, and our, resilience by sharing our stories of courageous men and women who refused to surrender. In these stories of this latter-day army of lovers lie gay America's heroic legacy, our hope, and our future.

THIRTY-NINE

Blue eyes dance above the gold oval rim of his glasses as he speaks. He looks at me, but I can see he's also looking beyond me, beyond the lilacs, azaleas, and rhododendron blooming outside the windows, through the door of memory to the place we revisit our lives' losses when jarred by a song, a photograph, a saved letter from a lost love, or a reporter's questions.

As a doctor, he was among the earliest people to know his HIV antibody status was positive, when the test became available in 1985. Until the viral load test was offered in 1996, now allowing us to monitor the virus's progression, he had no idea whether or when he would develop AIDS. For years, all he could really do was monitor his T-cell (CD4) count as HIV proceeded to slowly destroy his immune system, threaten his health, and make him susceptible to the cancers, pneumonia, brain inflammation, organ failure, and other infections that in 2007 alone killed 18,089 Americans⁹⁵⁸ and continue to kill an estimated two million people around the world each year.⁹⁵⁹

⁹⁵⁸. Centers for Disease Control and Prevention (CDC), Diagnoses of HIV Infection and AIDS in the United States and Dependent Areas, 2008. *HIV Surveillance Report*, 20 (2008).

⁹⁵⁹. Joint United Nations Programme on AIDS (UNAIDS), *Outlook Report 2010*. At http://data.unaids.org/pub/Outlook/2010/20100713_outlook_report_web_en.pdf, accessed 15 September 2010.

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He participated in the early ACTG 016 study of AZT in persons with HIV—which resulted in the approval of AZT “monotherapy,” a treatment that was only modestly successful in reducing the amount of virus in the body. Unfortunately AZT treatment then also had the effect of limiting future treatment options for those who took it.

In many people with HIV, fortunately not himself, the early cocktail treatments seemed highly toxic and often caused extreme side effects, including buildups of fat at the base of the neck (nicknamed “buffalo hump”) and the gaunt face and distended stomach of lipodystrophy (“crix belly,” it was called). Although he worried about possible reactions to his increasing number of medications, lost a lot of weight, and could have died from a few months of lactic acidosis because of the meds, he has been “remarkably free of discernible consequences” of his treatment.

He says that, as an HIV/AIDS physician, he “knew too much.”

“I assumed I was going to die,” he says.

He’d decided that when his CD4 count fell below three hundred, he would retire from his work at Madison Clinic, Seattle’s main public health clinic. There he worked around homeless and other people more likely to harbor multidrug-resistant tuberculosis and other opportunistic infections that could kill someone with HIV whose immune system was already struggling against the virus.

He’s scientific and detached in recounting his departure from the clinic, only mentioning he had tears in his eyes as he wrote his resignation letter. It’s when he speaks of his partner, David, that the memories he’s conjured make him choke up. He

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thinks he and David probably became infected with HIV in January 1983, when both had a mono-like illness for a couple of weeks, just as their relationship was beginning. In the early nineties David was diagnosed with cryptosporidiosis, a water-borne parasite that infects the small intestine, causes severe diarrhea, and can be deadly for a person with a compromised immune system. “I had a bunch of patients die of that in a very short period of time,” he says, noting his own now-tearful voice. “So I was getting ready to watch him die.”

David held on “quite a while,” and did well once combination antiretrovirals became the standard for managing HIV infection in 1996. Unfortunately, an unexpected effect of his rebounded immune system was its apparent rejection of his liver. He’d had a latent hepatitis C infection that suddenly progressed as his CD4 cell counts began to rise. “He died of AIDS because his immune system was screwed up, but he really died of hepatitis C, liver failure.”

As for himself? “I’m still alive.” He has also just retired, at age sixty-seven, after serving as Seattle and King County’s own AIDS “Czar” (as he jokingly puts it) since the first years of the epidemic. Bob Wood knows well it is an extraordinary achievement for someone still to be alive and thriving who has had HIV since way back then. “That’s a sea change,” he says.

He lists his “normal range” CD4 count of one thousand, and “almost totally controlled” virus, as evidence he is alive and well thanks to a complex regimen of powerful, and powerfully expensive, drugs that weren’t available—or even known about—twenty-five years earlier when he tested positive. He takes pills twice a day. “This is what I take at lunchtime,” he says, pointing out each colorful tablet in his pill organizer: Ritonavir; Lexiva; a multivitamin; an antidepressant; fish oil; Omeprazole for reflux; Loperamide (Immodium) for diarrhea. And in the evening: Epzi-

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com; an aspirin; niacin and Crestor for lipid control; Ritonavir; Lexiva; a calcium—"because those of us with HIV as we age lose calcium"—and vitamin D combination (he later stopped taking it because it has been found to possibly contribute to heart disease); an omeprazole; a couple more Loperamide.

And another glance through memory's door. "When it was lethal," he says, "and all my friends and patients were dying, that was a sea change every day because I'd lose someone every day, then get a new person who, like you and me, was anxious about what the future holds, saying, 'I'm young, am I going to die?' It was a miserable time."

Then, says Wood, "there was the sea change of being able to begin to measure the amount of virus and CD4 cells, and begin to realize that you could actually control the virus if you used a combination of drugs to combat this huge number of viruses in every part of your anatomy, your brain, your immune system; you're totally saturated with these viral particles." Wood says the latest change in the boiling sea that is the AIDS pandemic is "discovering that taking away the fear has increased the rate of new infections in the population."

By this point in our afternoon-long conversation, we've moved to the glassed deck off of Wood's second-floor study. A shimmering green northwest April afternoon surrounds us, sunshine glittering on the surface of Lake Washington a few blocks away. Somewhere on the other side is Bill Gates's house where Dr. Bob once saw a rainbow end and thought, "He doesn't need any more gold!"

"To my way of thinking," says Wood, holding ajar the door of memory, feet planted firmly in the moment, "HIV is still the worst, most terrible plague that could have hit the gay male population." Now reflective, he tells me, "It's really sad that the

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gay community doesn't appreciate that and is not dealing with it very effectively. It's fighting about 'Do I have to disclose?' 'Can't I just sero-sort instead of having to use a condom?' It's like a bunch of little sissies not recognizing the reality and tragedy." He pauses, then adds, "We are *still* the canaries in the coal mine."⁹⁶⁰

For those with the means to pay tens of thousands of dollars a year for medications, regular viral load and CD4 tests, medical specialists as needed, and a strong physical constitution able to withstand the side effects of the chemotherapies used to treat it, living with HIV can be as close to "normal" as we've ever seen it since AIDS was first reported in 1981.

Today in America's urban gay communities we don't regularly "see" AIDS around us. Unlike the eighties, we don't run into men we've known from the grocery store, the gym, or the gay parenting group suddenly emaciated and covered in the purple lesions of Kaposi's sarcoma. There aren't guys on crutches or in wheelchairs, like the men who led the second national gay and lesbian equal rights march in Washington and wept together on the National Mall while reading the names of their dead friends on the AIDS Memorial Quilt in October 1987. Even outspoken AIDS activists today get facial filler to repair the sunken-cheek lipoatrophy caused by some of the antiretroviral medications.

After thirty years, we're tired of our own anger and the grief of losing our friends. We're sick of seeing our young people continue to be bullied in school the way so many of us were when we were kids. We're worn down from having our families and relationships dismissed and illegal, of being forced to fight

⁹⁶⁰. Robert W. Wood, MD, interview with author, Seattle, 22 April 2010.

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for the equal justice our Constitution guarantees to all Americans.

No wonder it's appealing for apparently many gay and bisexual men to believe that popping a few pills a day is the worst that will happen if they are unlucky enough to get infected with HIV. No wonder so many believe that because a segment (mainly white and privately insured) of HIV-positive gay men are by and large doing well on treatment, we can check HIV off the list of gay America's most pressing concerns.

In fact, a 2009 Kaiser Family Foundation survey found a precipitous drop in Americans' view of AIDS as the nation's "most urgent" health problem. In 1995, the year before highly active antiretroviral therapy (HAART) became more widely used to manage HIV infection, 44 percent placed it at the top of the list; fourteen years later, only 6 percent ranked it as high. Clearly the public perception that treatment is available and works for everyone who needs it has been responsible for some of the changes Bob Wood speaks of.

But we have to ask whether the virtual disappearance of HIV/AIDS from the news, gay and mainstream, could also be shaping public opinion about what is described as the domestic (American) epidemic, our own share of the global pandemic. Kaiser found a 25 percent drop among white Americans who said they heard, saw, or read even "some" about HIV in the US. African-Americans and Latinos were more likely than whites to report hearing about HIV in the US, yet only half said they'd heard a lot about it.⁹⁶¹

⁹⁶¹. Kaiser Family Foundation, *2009 Survey of Americans on HIV/AIDS: Summary of Findings on the Domestic Epidemic* (April 2009).

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Unfortunately, out of sight and out of mind is too many Americans' preferred modus operandi. It is also the M.O. of many gay men with or at risk for HIV, even in hard-hit San Francisco. Kyriell Noon, a college professor-turned-activist/educator with waist-length dreads, a partner and child, is the director of gay America's premier HIV prevention education organization. For twenty-five years, San Francisco's Stop AIDS Project has pursued the singular mission of providing targeted, explicit prevention education for gay men, exactly what has been recommended by every credible public health expert since the beginning of the epidemic.

Noon told me how dismayed he is that HIV has become so seemingly commonplace in a place so harshly affected by it. "I have been surprised by how blasé so many men seem to be about HIV," Noon told me. "If they're positive, they seem blasé about transmission. If they're negative, they seem blasé about acquisition. If they don't know their status, they're blasé about that. Nobody seems to give a shit anymore. There is no urgency these days."⁹⁶²

A total of twenty-one people were living with AIDS in San Francisco in 1981, the first year AIDS was reported in the city. Three years later, Randy Shilts stunned the city when he reported in the *San Francisco Chronicle* a "Startling Finding on Gay Disease": One in 350 gay men in the city had AIDS.⁹⁶³ To-

⁹⁶². Kyriell Noon, interview with author, San Francisco, 16 April 2010.

⁹⁶³. James Kinsella, *Covering the Plague: AIDS and the American Media* (New Brunswick, NJ: Rutgers University Press, 1989), 262, 263.

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day, one in five gay and bisexual men in San Francisco is HIV-positive; as many as half of them don't know it.⁹⁶⁴

As of June 2010, AIDS had killed 19,199 San Franciscans. Nearly sixteen thousand more were living with HIV, 88 percent of them gay and bisexual men. Of them, 9,062 not only had HIV, but also had experienced at least one of the conditions that are considered "AIDS-defining." These "classic" markers of advanced untreated HIV disease date from the earliest years when people learned they had HIV only at the point they developed the purple lesions of Kaposi's sarcoma on their skin, or were rushed to the hospital with life-threatening *Pneumocystis carinii* pneumonia. The conditions still show up in considerable numbers of people diagnosed with AIDS in San Francisco.

Among the 9,062 with an AIDS diagnosis—bear in mind that classification as having AIDS doesn't end, even if the opportunistic infection itself is successfully treated—106 had Cryptococcosis, 318 had Kaposi's sarcoma, and 409 had *Pneumocystis*. This means these individuals were infected long enough for HIV to seriously damage their immune system to the point they were susceptible to life-threatening disease. By and large people with AIDS in the city (7,592) were diagnosed simply because their CD4 (T-cell) count was under two hundred. It's very likely they had no symptoms of HIV infection, so didn't realize

⁹⁶⁴. Centers for Disease Control and Prevention, "Prevalence and Awareness of HIV Infection Among Men Who Have Sex With Men—21 Cities, United States, 2008," *MMWR* 59(37) (24 September 2010), 1.

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they were infected—and hadn't a clue that they may already have infected someone else.⁹⁶⁵

Walking toward Market Street after finishing my interview with Kyriell Noon at Stop AIDS' Sanchez Street office in the Castro district, a poster on the Muni bus stop caught my eye. It showed a muscular white man's back. I focused on the words "Stay Negative" tattooed across the back of his hands, folded behind his head.

Clearly, San Francisco has not forgotten the plague that filled the bay with tears and forced its citizens to rise up and show the world what "traditional values" look like when they are practiced rather than preached. A stroll through the city's AIDS Memorial Grove reveals in the beautifully landscaped, serene seven acres within Golden Gate Park a deep ache in the heart of this city's gentle people. The words Healing, Hope, Remembrance are engraved in the granite pavers of the grove's Circle of Friends. Yet even here, in this sacred space honoring the memory of the many whose lives have been cut short, and the many more uninfected friends and family, still living, who have been forever changed by AIDS, it's also clear: We want to move on. On another stone is etched the Yiddish toast "L'Chaim—to Life," a reminder to live while we are alive. As early as 1995, Eric Rofes, then living in San Francisco, wrote in *Reviving the Tribe* that we were worn out by the need to keep constant vigilance and live in perpetual crisis.⁹⁶⁶

⁹⁶⁵. San Francisco Department of Public Health, *Quarterly AIDS Surveillance Report: AIDS Cases Reported Through June 2010*.

⁹⁶⁶. Eric Rofes, *Reviving the Tribe: Regenerating Gay Men's Sexuality and Culture in the Ongoing Epidemic* (New York: The Harrington Park Press, 1995).

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Today, astonishingly (yet not), HIV has become normalized in the culture of gay men in San Francisco, as HIV physician Christopher S. Hall told me. “They’ve assimilated messages about HIV being a chronic disease, almost like hypertension or diabetes,” he said.⁹⁶⁷

In Fort Lauderdale, where hundreds, perhaps thousands, of gay men with AIDS moved in the eighties and early nineties to live out their numbered days, longtime AIDS activist Mark S. King looks at his life with HIV in a video blog he calls “My Fabulous Disease.” One of his pieces was titled “My AIDS crisis is over.” King insisted in an interview it is “inaccurate and manipulative” to “scare” middle-class white gay men by using the word “crisis” to describe the state of the HIV epidemic among gay and bisexual American men. “You can’t say to gay men that HIV is a manageable disease, and you just go to the doctor, and watch your T-cells, and you can live like this,” said King. “You can’t say that and say AIDS is a crisis and if you get it you will get sick and die.” He continued, “One of those points of view is a trap, the point of view that the sky is falling. One of those is not the experience of gay white men in this country today. Those men have been making different decisions. Those men aren’t going to funerals all the time now.”⁹⁶⁸

Rick Siclari, director of Care Resource, the largest HIV service provider in South Florida, told me it’s a whole new world for middle-class white gay men⁹⁶⁹—even in his city of Miami,

⁹⁶⁷. Christopher S. Hall, MD, telephone interview with author, 6 May 2010.

⁹⁶⁸. Mark S. King, Skype interview with author, 29 April 2010.

⁹⁶⁹. Rick Siclari, telephone interview with author, 21 May 2010.

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with the highest rate of AIDS cases in the country.⁹⁷⁰ But white gay and bisexual men account for only 16.79 percent of the 32,710 AIDS cases reported in Miami-Dade County between 1981 and July 2010, and only one-quarter (24.7 percent) of the cases just among gay and bisexual men there. Hispanic and Black men are almost exactly equal, 40.46 percent and 41.27 percent respectively, in their share of the city and county's AIDS cases. All these men together account for 73.8 percent (53.7 percent Hispanics; 20.1 percent Blacks) of the city's men who have sex with men (MSM).⁹⁷¹

It may be a whole new world for the fortunate few, but for gay and bisexual men of color bearing the greatest brunt of AIDS in South Florida (and so many other areas of the country), the world doesn't look very different after all. It's not likely to change any time soon if it's left to the large national gay political groups in Washington working for gay equality. For years they have depended on AIDS-focused organizations to include gay and bisexual men in their own advocacy work; for years the de-gayd AIDS organizations have relegated gay men's needs to the sidelines.

Judging from the priorities of the wealthiest national gay political group, with its ubiquitous equal sign logo, it would seem that some are more equal than others. When Human Rights Campaign president Joe Solmonese in February 2010 outlined his organization's federal legislative priorities for the year, elim-

⁹⁷⁰. Centers for Disease Control and Prevention, *HIV Surveillance Report*, 2008 20 (June 2010).

⁹⁷¹. Miami-Dade County Health Department, *HIV/AIDS Surveillance: Monthly Surveillance Report* (July 2010). At <http://www.dadehealth.org/downloads/07-2010.pdf>, accessed 17 September 2010.

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inating the tax on domestic partner benefits and extending partner benefits for federal employees ranked high on the list. Surprisingly, given HRC's reputation among gay activists across the country as an elitist "white gay boys club," Solmonese said the group would also work to get earlier treatment for people living with HIV/AIDS "if they are on public assistance."⁹⁷² There was no mention of the need to challenge the shockingly low percentage of public HIV prevention money used to target MSM, even though gay and bisexual men are at greater risk than anyone else. There was no mention of the fact that HIV continues overwhelmingly in the US to afflict the men on whose behalf HRC purports to speak.

A visitor to HRC's website could reasonably conclude that the merest mention of the plague which annually kills thousands of American gay and bisexual men, including white gay men, was an afterthought at best. Buried in a "health" sub-page of the website were two outdated articles and an explanation as to why the organization had chosen to broaden its health focus beyond HIV/AIDS even though it "continues to be a priority for the LGBT [Lesbian, Gay, Bisexual and Transgender] community and for the Human Rights Campaign."⁹⁷³

"We follow the lead of HIV-specific organizations," explained HRC's chief legislative counsel Brian Moulton in an interview. I was handed off to Moulton after receiving no response to my

⁹⁷². Chris Johnson, "Solmonese Outlines 2010 Federal Legislative Agenda," *Washington Blade*. At <http://www.washingtonblade.com/2010/02/28/solmonese-outlines-2010-federal-legislative-agenda/>, accessed 8 September 2010.

⁹⁷³. Human Rights Campaign (website), http://www.hrc.org/issues/health/hiv_and_aids/hiv_and_aids_intro.asp, accessed 7 September 2010.

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request for an interview with Solmonese, and HRC's media spokesperson suggested I speak with an HIV organization instead of HRC. Moulton told me HRC had recently loaned its "heft" to successfully work with other organizations in pushing President Obama to lift the longstanding bans on federal funds for needle exchange programs proven to save the lives of injection drug users, and on HIV-positive persons coming to this country. Unfortunately these "victories" have little, if any, relevance to gay and bisexual American men.

Clearly HRC wasn't "hefty" enough to persuade the FDA to lift its blanket ban on blood donations from gay and bisexual men, a change that would have benefited those HRC says it represents. Moulton wasn't kidding when he said "large things" on HRC's agenda—he didn't mention the exceptionally large task of trying to change the president's mind about marriage equality, as he launched his 2012 reelection campaign—are "getting real traction" and "taking up the oxygen in the room." He added, "We don't do as good a job as we should highlighting HIV, and that could lead folks to think we're not focusing on these things."⁹⁷⁴

A couple of blocks from HRC's building in downtown Washington, D.C., I spoke with Darlene Nipper, deputy director of the National Gay and Lesbian Task Force. She told me that, like HRC, the task force relies on the expertise of HIV-specific organizations "to help us understand the best strategies so we can call for those and get our constituents to push for the right strategies that people with expertise in this area suggest we push for." Nipper noted a downside of the national gay groups handing off HIV as a priority issue to the specialized organizations. As you do that, she said, "there is the possibility of our

⁹⁷⁴. Brian Moulton, telephone interview with author, 28 April 2010.

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losing ground in some ways because not the whole community is focused on this, but a smaller segment of our community.”⁹⁷⁵

NGLTF considers itself the nation’s leading trainer of future LGBT activists and community leaders, a very small segment of the community with a potentially large influence. The task force’s signature annual activist training event, “The National Conference on LGBT Equality: Creating Change,” in 2010 offered sessions in thirty-one different categories ranging from aging to youth. Of the hundreds of conference workshops, seven focused specifically on HIV/AIDS, each one addressing an aspect of the epidemic. They included “HIV as We Grow Older: Policy Needs”; “Change We Can Believe In? LGBT Equality and HIV/AIDS Policy Under the Obama Administration”; “Enhancing HIV/STD Prevention Outreach to Diverse Communities: African-Americans, Hispanics, and Men Who Have Sex with Men”; “HIV and Young Gay and Bisexual Men and Transgender Women: Promoting Support”; “Advocacy, Community Mobilization and Outreach, Participation and the Rest of the Mess in HIV Clinical Research”; “What’s the Deal for Populations Most Impacted?”; and “HIV, Race and Generational Differences.”⁹⁷⁶

There was no workshop to equip budding young activists with an understanding of the historical impact of HIV/AIDS on the gay community; the fact that HIV stigma in the US contin-

⁹⁷⁵. Rev. Darlene Nipper, interview with author, Washington, DC, 25 March 2010.

⁹⁷⁶. National Gay and Lesbian Task Force, “The National Conference on LGBT Equality: Creating Change,” Dallas, TX (3–7 February 2010). Conference program at http://www.thetaskforce.org/downloads/creating_change/cc10/cc10_program_book.pdf, accessed 27 September 2010.

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ues to be driven by ignorance about basic HIV transmission and shaped by the early connection of HIV and gay men; the persistent shortchanging of prevention funding targeted at gay and bisexual men despite our vastly higher risk for HIV than any other group in America; or that explained why it is inaccurate and counterproductive to speak of African-Americans, Latinos, and “men who have sex with men” as if they are mutually exclusive, rather than overlapping, categories. Granted, this was just one training conference. But this particular conference is the largest LGBT activist training conference in the world. It would seem that a solid grounding in recent gay community history, particularly the reasons AIDS drove and built the gay political movement, is essential for anyone wishing to become a leader in that movement.

A better measure of the task force’s involvement with HIV issues of gay and bisexual men on a day-to-day, year-round basis might be to conduct a simple inventory of its press releases, let’s say for 2009. Only four of the 105 releases the task force issued over the year dealt with HIV/AIDS. In January, there was a call to action outlining the plenary session and workshops on HIV-related subjects for up-and-coming activists who would be attending the “Creating Change” conference. Pope Benedict was criticized for claiming that greater condom use would increase AIDS. President Obama was praised for finally ending the federally sanctioned stigma codified in the

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longstanding ban on HIV-positive visitors to the country. And World AIDS Day was marked.⁹⁷⁷

Even longtime observers and activists question the apparent dropping of HIV/AIDS as a top priority of the organized gay political groups. “The lack of access to marriage is not exactly a crisis,” said noted gay historian John D’Emilio in an interview. “But think of the mobilization and energy that has gone into that in the last five to ten years as opposed to an issue in which thousands of people are dying each year. AIDS is much more of a crisis than marriage.” D’Emilio wrote in a 2006 commentary in the *Gay & Lesbian Review Worldwide* that the marriage fight is setting us back. “Please, can we speak the truth?” he wrote. “The campaign for same-sex marriage has been an unmitigated disaster. Never in the history of organized queerness have we seen defeats of this magnitude.”⁹⁷⁸ He believes the national gay movement is swimming against a historical tide that is washing aside traditional definitions of coupled domestic relationships.

⁹⁷⁷. National Gay and Lesbian Task Force, “Call to Action on HIV/AIDS at the National Conference on LGBT Equality: Creating Change, Jan. 28–Feb. 1” (News release, 14 January 2009), at http://thetaskforce.org/press/releases/pr_011409; “Task Force Condemns Pope’s Remarks on Condoms” (News release, 17 March 2009), at http://thetaskforce.org/press/releases/pr_031709; “Task Force: Lifting HIV Travel Ban Will Finally End ‘Federally Sanctioned Stigma’” (News release, 20 October 2009), at http://thetaskforce.org/press/releases/pr_103009; and “Marking World AIDS Day 2009,” (News release, 1 December 2009), at (http://thetaskforce.org/press/releases/pr_120109). All news releases were accessed online on 8 September 2010.

⁹⁷⁸. John D’Emilio, “The Marriage Fight is Holding Us Back,” *The Gay & Lesbian Review Worldwide* (November–December 2006).

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Birth control, cohabitation, feminism, and the necessity of double-income households have upended the meaning of marriage, even for heterosexuals.

“Marriage appeals to people who have social and economic status,” D’Emilio told me. “AIDS hits more strongly people who don’t have economic status.” He said that over the last decade “AIDS dropped off the face of the gay map.” He explained, “It’s not that national organizations and state organizations do nothing about it, but it’s not a priority. It gets a lot less attention than ‘Don’t Ask, Don’t Tell’ and ENDA [the proposed, not passed, Employment Non-Discrimination Act], and, in the last few years, marriage.” As for focusing so narrowly on marriage equality when so many gay and bisexual men are still at risk for infection and death in a continuing plague, D’Emilio said, “I find myself disturbed and shocked by it. It displays an enormous lack of gratitude on the part of the gay community to the people for whom AIDS still matters.”⁹⁷⁹

AIDS still matters for Lorri Jean. In her sunny corner director’s office at the Los Angeles Gay and Lesbian Center, Jean’s mood darkens as she describes a recent invitation-only retreat she attended for the leaders of LGBT organizations from across the country. “HIV/AIDS wasn’t on the agenda,” she said, “and hasn’t been on the agenda for a long time.”⁹⁸⁰

Of course there are reasons why HIV/AIDS has taken a back seat to issues some gay people consider more important. Foremost, of course, is the overall success of medical treat-

⁹⁷⁹. John D’Emilio, telephone interview with author, 18 August 2010.

⁹⁸⁰. Lorri L. Jean, interview with author, Los Angeles, 13 April 2010.

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ment for those able to access and comply with it. Then there is the challenge of keeping a thirty-year-old story new and relevant to young gay men in particular, while reminding older men that although the medical picture looks better for many with HIV, a positive antibody test result is still a death sentence for the overwhelming majority of people living with the virus in this world.

With few exceptions, even the gay media can't be relied on to keep HIV on the front burner. Although 2006 saw a flurry of news coverage pegged to the epidemic's twenty-fifth anniversary, the *San Francisco Chronicle* that year reported findings of a recent survey of gay journalists indicating that AIDS ranked third among their top interests, behind same-sex marriage and the Catholic Church's stance on gay priests, but ahead of crystal meth and *Brokeback Mountain*.⁹⁸¹

The very language used to speak about gay and bisexual men has contributed to the dangerous belief that HIV is no longer an important issue for us. "No one identifies as 'MSM,'" said Lorri Jean. The CDC and other government and scientific bodies use the generic term to include the range of men from the openly gay to the men who don't identify themselves as gay although they have sex with other men. Much ink has been spilled and talk show tempers ignited in discussions of the so-called "down low," men who secretly have sex with other men. Although men of all skin colors have been known to secretly engage in same-sex relations, the stereotype dies hard of men of color being supposedly more prone to engage in "DL" behavior. Nevertheless, said Jean, "Plenty of people of color identify as gay or bisexual." She recalled that in the early years of AIDS when "no one would pay attention to the epidemic because of

⁹⁸¹. Wyatt Buchanan, "How AIDS Changed Us," *San Francisco Chronicle* (4 June 2006).

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whom it was affecting,” gay leaders emphasized that it could affect anyone, not just gay men. It was also important for prevention messages to emphasize that certain behaviors, not personal identity, put one at risk. So the clinical term “MSM” became shorthand and all-encompassing and resulted in stripping gay and bisexual men of personal identity and connection to a larger community. This de-gaying also perpetuated the falsehood that the “sex” part of MSM could be glossed over.

As three decades of AIDS were marked in 2011, it was startling to see the degree to which Americans’ notoriously short memories had already begun to airbrush away the experience of their gay countrymen’s devastation and defiance in the plague years. Used by now to thinking of the “face” of AIDS as that of an impoverished, dark-skinned African woman or baby, even the nation’s best-educated young people seem not to be aware of the plague’s impact here in their own homeland, beginning in the very decade when many of them were born.

“The de-gaying thing really worked,” said author and Dartmouth College professor Michael Bronski. “For better or worse, we did our jobs.” As evidence, Bronski described a class about AIDS he taught, called “Plagues and Politics.” He said his students couldn’t understand why he spoke of AIDS as a “gay disease.” Even a lesbian student told him, “I thought it was a little weird you were talking so much about ‘gay.’” She believed AIDS “was Africa and inner-city drug users, but mostly Africa.” Another student said, “I was wondering how you were going to bring in the U.S. part.”⁹⁸²

Young gay men can be forgiven for not knowing the details of their community’s recent travails. They didn’t live through the

⁹⁸². Michael Bronski, telephone interview with author, 8 September 2010.

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nightmare, after all. At the start of the millennium, the *New York Times* noted that a generation of young gay men had by then already come of age without seeing their peers suffer and die from the horrific and disfiguring effects of HIV before HAART brought such dramatic change for many of those living with the virus.⁹⁸³

Older gay men, many having lost lovers and friends and possibly living with HIV themselves, seem to prefer pleasanter subjects to the horrors we lived through. It's understandable, to an extent. Like returning war vets, the grief and shock sustained by our wounded warriors keeps so many of us silent. Unfortunately our silence means our younger brothers are far less likely to learn about the bravery, courage, and creativity with which our people faced the fight of our lives, for our lives. "Gay men in their forties and fifties don't want to talk about AIDS," said longtime activist and former National Gay and Lesbian Task Force director Urvashi Vaid. Hundreds of men in that very age group streamed by as we talked on a brilliant August Saturday outside Joe, the Provincetown coffeehouse. They looked festive, if grayer and a bit less slender than when we partied in our twenties at the Boatslip's daily tea dance. "We all have PTSD [post-traumatic stress disorder]," said Vaid.⁹⁸⁴

Our silence means the organizations we created to care for our sick and dying friends and neighbors are struggling to raise funds as they continue to care for people with HIV. In Miami, Rick Siclari said, "White gay men are not giving as much today." Now the agency is hoping its new clients, many of them

⁹⁸³. Erica Goode, "With Fears Fading, More Gays Spurn Old Preventive Message," *New York Times* (19 August 2001).

⁹⁸⁴. Urvashi Vaid, interview with author, Provincetown, Mass., 7 August 2010.

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Black and Latino, will participate in fundraising by giving them the chance to make smaller donations in the five to ten dollar range.⁹⁸⁵

It's as if we haven't learned one of the most important lessons that we ourselves taught the world: "Silence = Death," as ACT UP famously put it. It would seem that silence is inexcusable when gay and bisexual men of all races continue to bear the overwhelming brunt of the American AIDS epidemic. Extraordinary numbers of us continue to become infected with HIV. And thousands of our brothers each year are still dying from AIDS because they don't know their HIV status until it's too late. They likely don't have the means to access life-saving medical treatment or the stable life needed (including housing) to use it properly, or else their bodies simply don't respond to the medication.

In 2010, the CDC released figures showing that, although the agency estimates gay and bisexual men to account for only 2 percent of the U.S. population over age thirteen, we are sixty times more likely than heterosexual men and fifty-four times more likely than women to be diagnosed with HIV.⁹⁸⁶ We account for 48 percent of the more than one million people living with HIV in the United States, an estimated 532,000 men. We comprise nearly half (48 percent) of all new HIV infections in the U.S., an estimated 28,700 new infections a year. In twenty-one major U.S. cities, one in five gay men is HIV-positive. Of 8,153 gay and bisexual men tested in the cities, 1,562 were

⁹⁸⁵. Siclari interview.

⁹⁸⁶. DW Purcell, C Johnson, A Lansky, J Prejean, R Stein, P Denning, Z Gaul, H Weinstock, J Su, & N Crepaz, Latebreaker #22896 Presented March 10, 2010, 2010 National STD Prevention Conference; Atlanta, GA.

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positive. In Baltimore, 38 percent were positive; 29 percent in New York City; 26 percent each in Dallas and Houston; Miami, 25 percent; 23 percent in San Francisco; and 21 percent in New Orleans.⁹⁸⁷

HIV infection has steadily increased among gay and bisexual men in the United States since the early nineties, even as it has decreased among heterosexuals and injection drug users. Most new infections among Black and Hispanic gay/bi men are among young men between thirteen and twenty-nine. Young Black MSM are twice as likely as their white and Hispanic peers to get HIV. White gay/bi men are mostly being diagnosed in their thirties and forties. Half of all infected gay/bi men don't know they are HIV-positive. More than two-thirds of infected Black men, and nearly 80 percent of HIV-positive young men aged eighteen to twenty-four, are unaware they have the virus. And there is still the death toll of AIDS, in spite of medical advances that have allowed many to live well with HIV rather than die in short order from AIDS. By the end of 2007, AIDS had killed an estimated 282,542 gay and bisexual men in America, most in the prime of life.⁹⁸⁸

Longtime Los Angeles gay activist David Mixner in August 2010 called it the best and worst moment in the plague's three decades. "The good news is indeed reason to celebrate," he said. "Real progress is being made in fighting this disease." As

⁹⁸⁷. CDC, "Prevalence and Awareness of HIV Infection Among Men Who Have Sex With Men—21 Cities, United States, 2008."

⁹⁸⁸. CDC, *HIV and AIDS Among Gay and Bisexual Men*, (Fact sheet, June 2010); CDC, *HIV Among Gay, Bisexual and Other Men Who Have Sex with Men (MSM)*, (Fact sheet, September 2010).

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for the bad news, Mixner said the recessionary economy was “wrecking havoc with HIV/AIDS budgets, international funds to fight HIV, research and treatment and care.” In particular, Mixner noted that the federal AIDS Drug Assistance Program (ADAP) has either cut back or frozen in place. “Unless this situation is totally corrected,” said Mixner, “it could mean a death sentence for some people with HIV/AIDS.”⁹⁸⁹

At the time of Mixner’s comments, more than three thousand individuals in this country were on ADAP waiting lists in thirteen states, hoping the program would enable them to receive the life-saving medications they can’t afford on their own. As this book goes to press, in early summer 2011, the Kaiser Family Foundation reports that eighty-one hundred Americans were now on the ADAP waiting lists across the country.⁹⁹⁰ Without guaranteed access to HAART for everyone who is HIV-positive and can’t afford the expensive medications on their own, any hope of treating our way out of the epidemic is wishful thinking. And for those with HIV denied the medication they need to suppress the virus—rendering them less infectious—the chance of developing horrific illness and death from AIDS increases with each passing day, even in 2011.

In the summer of 2010, the Presidential Advisory Council on HIV/AIDS called on President Obama and Secretary of Health and Human Services, Kathleen Sebelius, to work closely with Congress to provide adequate emergency federal ADAP fund-

⁹⁸⁹. David Mixner, “HIV/AIDS: The Best of Times and the Worst of Times,” *Huffington Post* (21 August 2010).

⁹⁹⁰. Kaiser Family Foundation, AIDS Drug Assistance Programs (ADAPs) with Waiting Lists or Other Cost-Containment Strategies, as of May 2011, at [http://www.statehealthfacts.org/com-
paretable.jsp?ind=552&cat=11](http://www.statehealthfacts.org/com-
paretable.jsp?ind=552&cat=11), accessed 14 June 2011.

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ing in the current fiscal year (\$126 million) to eliminate wait lists, reverse cost-containment measures, and meet the increased demand for treatment. PACHA further asked for adequate federal Ryan White CARE Act funding in fiscal 2011 and beyond to meet the growing need for the care, treatment, and essential support services the Ryan White program supports. Finally, the council asked for immediate expanded access to Medicaid for people with HIV through the enactment of the Early Treatment for HIV Act. PACHA noted that although the Patient Protection and Affordable Care Act of 2010 “will greatly improve access to affordable, high quality health care for many people living with HIV and AIDS,” most of the provisions relevant for people with HIV do not take effect for years to come. This means insurance companies will be allowed to continue denying coverage to people with HIV and other pre-existing conditions until the practice is finally banned in 2014.

For now, health care reform means that if people who are currently uninsured want and can afford the high premiums of private insurance, they are by and large limited to a group policy or a state risk group plan. Some Medicare provisions affecting lower-income people won’t go into effect until 2020. Though not speaking directly of the crazier-than-ever quilt of an American health care system, PACHA understatedly said, “People living with HIV and AIDS confront significant barriers to access to care and treatment right now.”⁹⁹¹

Not all the barriers to effectively managing HIV disease are the result of being uninsured or poor. Even HIV-positive white middle-class gay men with private insurance aren’t all doing

⁹⁹¹. Presidential Advisory Council on HIV/AIDS, Resolution Regarding Timely Access to Life-Saving Care and Treatment. At <http://www.aids.gov/federal-resources/policies/pacha/meetings/june-2010-resolution.pdf>, accessed 11 September 2010.

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nearly as well on HAART as the treatment triumphalists want to believe. Dr. Christopher Hall told me, “The reality is that, in general, the clinical management of the disease has evolved tremendously beyond where we were in the eighties.” Yet Hall still sees patients with many challenges they wouldn’t have without HIV. “It’s not commonly the case,” he said, “that someone finds out about their infection, begins on therapy and experiences no inconvenience or setback on that therapy. There are setbacks. I think people miss that. They don’t appreciate the inconvenience of having to take meds once or twice a day. They don’t appreciate the burden of having an infection that is potentially transmissible, or what it means for relationships, for disclosure. They don’t think about the inconvenience of having to make medical visits three or four times a year.” They also are unlikely to understand the sharply increased risk of people with HIV, as we age, for cancers, heart disease, organ damage, changes in body shape, and any number of other potentialities we don’t yet know about because long life with HIV is still a new concept. Many of those risks stem from the cumulative effects on the body of long-term chemotherapy, which is exactly what HAART is.⁹⁹² “Not everybody is going to have that easy a walk with HIV,” said Hall. “The public perception has evolved almost to ignore that there are still individuals and communities for whom HIV is just as destructive and debilitating as it ever was. It’s hard to convey that complexity in the sound bites and billboards.”⁹⁹³

Is there still an AIDS crisis in gay America? It depends on

⁹⁹². Gay Men’s Health Crisis (GMHC), *Growing Older with the Epidemic: Aging and HIV* (2010). At http://www.gmhc.org/files/editor/file/a_pa_aging10_emb2.pdf, accessed 13 September 2010.

⁹⁹³. Hall interview.

VICTORY DEFERRED

who you are, said Sarah Schulman, a noted ACT UP/New York activist, author, and college professor. “If you are someone who can afford these treatments, and you have the lifestyle that enables you to take them appropriately, then you can live a full life having to tolerate a lot of pretty awful side effects. But that profile does not apply to most PWAs [people with AIDS] in the world.”⁹⁹⁴ In fact, the estimated 532,000 gay and bisexual men living with HIV in the United States as of 2010 comprise a mere sliver, less than one in sixty-three, of the 33.4 million living with HIV worldwide.⁹⁹⁵ Of course, as CDC has reported, the actual number of HIV-positive gay and bisexual men is likely much higher since this figure only accounts for known cases; it estimates that another 50 percent are believed not to know their HIV status. We don’t know for sure how many are receiving treatment, though worldwide, five million people total are on HAART.⁹⁹⁶ The rest will likely sicken and die of what are mostly preventable AIDS-related causes.

Gregg Gonsalves, a former ACT UP/New York member and still a noted HIV treatment activist, returned to Yale to finish the bachelor’s degree he had put aside when AIDS became his passion in the early nineties. He’s living well with HIV, but

⁹⁹⁴ Sarah Schulman, telephone interview with author, 1 July 2010.

⁹⁹⁵ Joint United Nations Programme on HIV/AIDS (UNAIDS), *’09 AIDS Epidemic Update*. (November 2009), at http://data.unaids.org/pub/Report/2009/JC1700_Epi_Update_2009_en.pdf, accessed 9 September 2010.

⁹⁹⁶ Joint United Nations Programme on HIV/AIDS (UNAIDS), *UNAIDS Report on the Global AIDS Epidemic 2010*. At http://www.unaids.org/documents/20101123_GlobalReport_em.pdf, accessed 14 June 2011.

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knows that only continued access to effective treatment and medical care will keep him well. He minces no words. “After 1996,” said Gonsalves, “when the drugs came on line, it was like gay men packed up their bags and went home. Now they could live normal, middle-class, privileged lives.” AIDS in America at the opening of the twenty-first century’s second decade, thirty years since it was first reported among urban American gay men, isn’t only about gay vs. straight, or even white vs. Black. “It’s about class,” said Gonsalves.⁹⁹⁷

Phill Wilson knows exactly what Gonsalves is talking about. The founder and director of the Los Angeles-based Black AIDS Institute, Wilson has lived with HIV since the 1980s. A tireless advocate, he has for years sounded the alarm among disproportionately affected African-Americans, and championed full equality for gay and bisexual men of color within a national gay community that too often overlooks those who aren’t white and middle-class. Wilson speaks of the gay community as one who considers himself a part of it. But he makes clear the differences between the experience of most middle-class white gay men with HIV and that of poor and working-class people of color, including many gay and bisexual men, who account for an expanding share of those living with HIV in this country.

“What happened in gay America in the early eighties,” said Wilson, “was that here was this community that was beginning to move along, and then AIDS happened. So the entire community could focus on one thing, and it became a requirement that to be part of the community you had to focus on AIDS. If you were a gay bar and you didn’t focus on AIDS, the gay community closed you down. If you were a clothing store and you didn’t have an AIDS component, we would close you down.

⁹⁹⁷. Gregg Gonsalves, Skype interview with author, 25 August 2010.

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So you had to focus to be part of the community.” He said another important reason the gay community was able to mount early, strong responses to HIV was that it was what he called a “democratic community.” He explained, “There was a class integration in gay society. So there were people who were wealthy who understood this was an important issue for them.” Putting a finer point on it, he added, “You could be a millionaire or homeless, but once you showered and got naked and put the towel on in the bathhouse, you were all the same. So everybody on some level, whether they are willing to describe it in those graphic terms, understood.”

Wilson said that, by contrast, in poorer communities there hasn’t been the same kind of economic integration. “There just aren’t as many Sheldon Adelsons or David Geffens or Tim Gills who can come on board,” he said. Poor communities, people of color in general, said Wilson, “don’t have the luxury of focusing on one thing because when AIDS enters the home; cancer doesn’t go away; diabetes doesn’t go away; violence doesn’t go away; teen pregnancy doesn’t go away; poverty doesn’t go away; underemployment doesn’t go away; unemployment doesn’t go away. None of those things go away.” Wilson concluded, simply, “AIDS in America today is a Black disease.”⁹⁹⁸ In fact, Blacks account for nearly half of all Americans living with HIV (46 percent, nearly four times their 12 percent share of the total population), and by the end of 2007 accounted for 40 percent of the 562,793 Americans who had died from AIDS to that point.⁹⁹⁹

⁹⁹⁸. Phill Wilson, interview with author, Los Angeles, 12 April 2010.

⁹⁹⁹. Centers for Disease Control and Prevention (CDC), *CDC HIV/AIDS Facts: HIV/AIDS Among African Americans* (Updated August 2009).

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In 2008, the CDC announced that its long-held estimate of 40,000 new HIV infections a year in America was too low. Now, said the agency, 56,300 were believed to become infected each year in this country. White, followed closely by Black, gay and bisexual men still account for the largest number of annual new HIV infections of any group in the U.S. The CDC estimated that 45 percent of new HIV infections were among Blacks, two-thirds (65 percent) of whom were men. Most of the men (63 percent) reported having unprotected sex with another man. Another 17 percent of those newly diagnosed were Latino, 76 percent of them male, 72 percent of them reporting same-sex behavior. White gay men accounted for close to half (46 percent) of all new HIV infections among gay or bisexual men.¹⁰⁰⁰

HIV infection and AIDS—more accurately, advanced untreated HIV disease—are strongly associated with poverty and living in concentrated urban poverty areas in the nation's major cities. Overall, 46 percent of Blacks and 40 percent of Hispanics live in these urban poverty areas compared to just 10 percent of whites.¹⁰⁰¹ According to the CDC, blacks and Hispanics in these areas had about the same high prevalence of HIV. Compared to the overall U.S. population, though, Blacks have more than eight times, and Hispanics three times, as much HIV

¹⁰⁰⁰. H.I. Hall, R. Song, P. Rhodes, J. Prejean, Q. An, L.M. Lee, R.S. Janssen, Estimation of HIV Incidence in the United States, *Journal of the American Medical Association* 300(5) (2008): 520–529.

¹⁰⁰¹. US Census Bureau, “Areas with Concentrated Poverty: 1999,” *Census 2000 Special Reports* 2005.

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as whites.¹⁰⁰²

Despite the well-documented fact that HIV in the US still overwhelmingly affects gay and bisexual men of all races, Lorri Jean recalled a “controversial” public education campaign the LA Gay and Lesbian Center launched in 2006 to underscore the fact. It featured posters and print ads that said, “AIDS is a gay disease. Own it. End it.” In fine print, the materials made clear that, although HIV can affect anyone, it has affected gay and bisexual men in this country much harder than any other group. Some other gay groups protested, accusing the center of being homophobic for calling AIDS a “gay” disease after years of promoting the fact that it could affect anyone. Fundamentalists Christians, still looking for excuses to flout Christ’s teachings to love others and care for the sick by hating and persecuting gay people in the name of their lord, said, “We told you so.”

Gay-bashing religionists were nothing new. “But what’s shocking,” said Jean, “is that even our own community doesn’t understand the impact on our community.” She said that in focus groups of gay men in Los Angeles and San Francisco before the campaign, everyone was shocked to learn that 75 percent of the people living with HIV in California are gay and bisexual men. Young people, she said, are coming out into a world that has few HIV prevention programs geared toward them and coming out into a gay community “that’s not talking about it.” Jean contrasted their experience with our own. “When you and I first met,” in the mid-eighties, she said, “it was not possible to have a gathering of more than one gay or lesbian person where you were not talking about HIV/AIDS. There was

¹⁰⁰². Centers for Disease Control & Prevention (CDC), “HIV Prevalence Estimates—United States, 2006,” *MMWR* 57 (2008):1073-76.

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not a dinner I went to that didn't have HIV/AIDS as part of the conversation. Now it seems to have all gone into the closet." Jean said that after the "AIDS is a gay disease" campaign, the Los Angeles city AIDS office did its own campaign with billboards all over the city saying, "HIV is a Black disease," "HIV is a women's disease," and "HIV is a Latino disease." Jean asked, "What's the only community they left out? No billboard ever said 'HIV is a gay disease.' Now how shocking is that? We raised holy hell about that."¹⁰⁰³

Charles King is a man used to raising holy hell. In July 2010, the ordained Baptist minister, formerly with ACT UP, co-founder and currently CEO of New York's Housing Works, horrified other AIDS advocates gathered for a reception at the White House to celebrate the president's just-unveiled plan for tackling AIDS in the United States. "Mr. President!" shouted King, as President Obama addressed the group. The president told him to speak with him after his remarks. King later explained that he wanted the chance to point out that the goals of the new national strategy weren't ambitious enough, the waiting lines for the AIDS Drug Assistance Program were a crime, and failing to address housing and homelessness would doom the plan to failure.

After the president finished congratulating the assembled group (and of course his own administration) for helping to develop the nation's first plan to coordinate its response to HIV in the epidemic's thirty-year history, he spoke briefly with King. "I know this isn't everything we need to do," Obama told King, "but it is a start." King assured the president he'd read the plan, then told him, "This really isn't enough. We really need your

¹⁰⁰³. Jean interview.

VICTORY DEFERRED

leadership.” Obama promised he would give his leadership.¹⁰⁰⁴

In a later interview, King said the national gay organizations haven’t provided leadership on HIV/AIDS for years because “the community follows its dollar.” Since most of the dollars contributed to HRC and NGLTF come from white gay men and lesbians, “that’s who sets the agenda and decides what’s important for the community,” said King. At the top of their agenda, of course, has been marriage equality. King said the groups want to embrace the things that make us ‘normal.’ “So gay marriage is the issue of the day as opposed to why it is that Black gay men or young people are still being infected with HIV. We’re not sure we want to claim them as our own. We have a way of disassociating ourselves from particular groups of people,” said King, “and saying they aren’t part of our community; they don’t count.” He added, “Once [HIV] came to be seen as something that in middle-class gay communities was a chronic, treatable, manageable issue, it went off the radar screen of what the organized political community cared about, and I think that remains the case.”

But the medical success stories aren’t the only reason HIV has disappeared from view. King said addressing the epidemic has become more complicated. “It was very simple back in the days of ACT UP,” he said, “when it was a ‘drugs into bodies’ type thing. Now when we talk about the domestic epidemic, we have to talk about homelessness. We have to talk about drug use and addiction, and how those things are some of the drivers. We have to talk about poverty and how it’s a driver. I think those things become too complicated for the organized gay

¹⁰⁰⁴. David Thorpe, “Housing Works CEO Charles King Interrupts Obama AIDS Speech, Leading to Face-to-Face Exchange.” Published at TheBody.com (<http://www.thebody.com/content/art57430.html>), accessed 10 September 2010.

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community that doesn't want to be identified with drug addiction and those things, even though the reality is that our community probably struggles with issues around addiction and similar kinds of things because of the general oppression that people experience in their day-to-day lives. But we don't want to be perceived that way, so we kind of ignore that dirty little secret."¹⁰⁰⁵

Surely the dirtiest of gay America's secrets can't compete with the openly known fact that thousands of Americans will die of preventable illness if ADAP programs aren't funded to the level needed. And surely it can't compete with the much less publicized fact that, as Americans waited in line not knowing if they would live or die, the American people, through the President's Emergency Plan for AIDS Relief (PEPFAR) program, generously paid to give free HIV medications to an additional seventy-two thousand Ugandans.¹⁰⁰⁶ Fortunately for them, American generosity didn't depend on the outrage of gay Americans when Uganda came close to adopting laws that would have sentenced gay people to death simply because of the shame the country's leaders feel knowing there are same-sex-loving people among them, thereby contradicting their claim

¹⁰⁰⁵. Charles King, telephone interview with author, 8 September 2010.

¹⁰⁰⁶. Hilary Bainemigisha, "72,000 More to Get Free AIDS Drugs," *The New Vision* (3 September 2010). At <http://www.newvision.co.ug/D/8/13/730818>, accessed 11 September 2010.

VICTORY DEFERRED

that homosexuality is a western “sickness.”¹⁰⁰⁷

Of course we should be glad that seventy-two thousand more human beings would have the chance to live with HIV rather than die from AIDS. But it would seem that, even in a global pandemic, charity should begin at home. Here at home, the plague continues. Here at home, stories abound of poor Black and Hispanic Americans—including gay people—being discouraged from getting tested for HIV because there is no guarantee they can access treatment if they test positive, and because there is still so much stigma of knowing their HIV status, even in hard-hit communities of color. The Black AIDS Institute reports that 70 percent of Blacks surveyed in 2009 reported that no doctor or health care provider had ever recommended they be tested for HIV. Many providers apparently don’t encourage testing if they are unlikely to be reimbursed for the cost. The institute said the issue is further complicated by the fact that Blacks and Latinos are more likely to seek primary care through emergency room visits, where doctors are less likely to recommend HIV testing.¹⁰⁰⁸

Dana Van Gorder in early 2010 was startled and dismayed while speaking on a Berkeley radio program with a group of HIV service providers from Oakland, just across the bay from San Francisco. He said the HIV epidemic in Oakland is similar to, yet different from, San Francisco’s in that it’s a lot of men

¹⁰⁰⁷. Xan Rice, “Uganda Considers Death Sentence for Gay Sex in Bill Before Parliament, *The Guardian* (29 November 2009). At <http://www.guardian.co.uk/world/2009/nov/29/uganda-death-sentence-gay-sex>, accessed 13 September 2010.

¹⁰⁰⁸. Black AIDS Institute, *Passing the Test: The Challenges and Opportunities of HIV Testing in Black America*, (Los Angeles: Black AIDS Institute, June 2009).

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who have sex with men who are not white. The director of Project Inform, the San Francisco group that since 1985 has provided HIV-related information to help people live well with HIV, said the providers were ignorant of basic laws to protect people with HIV against discrimination and government-backed programs to serve them. Van Gorder said that at the end of the show, “If I had been a person who didn’t know their HIV status, or who knew their serostatus but who hadn’t engaged in treatment for some reason, I would have pulled the blanket over my head.”

Van Gorder recalled the providers talking about a woman coming in for HIV testing who was worried about losing her job. “I told them this was confidential information,” said Van Gorder. “She could go to a confidential testing site, there are laws protecting her, and legal services. We have medications that could save her life.” But they told her nothing. “They let her walk out, basically. They complained so bitterly about how ‘The system is falling apart, and there is no money.’ You wouldn’t have known there is an AIDS Drug Assistance Program. You wouldn’t have known there is a Ryan White CARE Act. You wouldn’t have known that you should go to the clinic no matter what. Sure there could be harm from others knowing she has HIV. But which is worse, being victimized by others’ fear and ignorance, or risk serious illness and death by not pursuing treatment?”¹⁰⁰⁹

Shawn Lang, a lesbian and longtime, highly respected AIDS activist, is the policy director for the Connecticut AIDS Resource Coalition (CARC) in Hartford. She told me in an interview, “As long as people are getting infected, it is still a crisis.” The crisis isn’t only in the medical emergency that an HIV diagnosis unleashes. For many of those being diagnosed today,

¹⁰⁰⁹. Dana Van Gorder, interview with author, San Francisco, 19 April 2010.

VICTORY DEFERRED

immediate needs such as food, shelter, a job, and transportation, are more pressing than something that may not make them sick for years. Even in one of the wealthiest states in the nation, Lang said about 40 percent of the people known to be living with HIV in Connecticut (10,574 as of December 2009¹⁰¹⁰) are on Medicaid, the federal-state insurance program for low-income citizens.

The federal Ryan White CARE Act is authorized only until 2013. Although it has been regularly reauthorized since it was passed in 1990, there is no guarantee this time. Hundreds of thousands of people with HIV, and millions more at risk of contracting it, could be stranded without insurance before the health reform measure takes effect in 2014, finally guaranteeing adults can buy health insurance in spite of a pre-existing condition. "It's an uncertain time," said Lang.¹⁰¹¹

If ever Charles Dickens' oft-quoted *A Tale of Two Cities* opening line deserved quotation, the state of gay life and the HIV epidemic in America thirty years after it was first reported surely warrant it: "It was the best of times, it was the worst of times." Thousands in this country can live with HIV because of HAART, even as millions continue to die from AIDS because of where they happen to live in this world. Gay Americans enjoy expanding equality, yet we continue to be regarded and legally classified as second-class citizens.

On October 28, 2009, President Obama signed into law the

¹⁰¹⁰. Connecticut Department of Public Health, *Connecticut HIV/AIDS Statistics Through 2009*. At <http://www.ct.gov/dph/cwp/view.asp?a=3135&q=393048>, accessed 13 September 2010.

¹⁰¹¹. Shawn Lang, interview with author, Hartford, Conn., 6 July 2010.

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Matthew Shepard and James Byrd, Jr. Hate Crimes Prevention Act (HCPA), more than a decade after Shepard's brutal murder in 1998 for being gay and Byrd's savage murder the same year simply because of his skin color. A federal judge in California on August 4, 2010, overturned the state's 2008 ballot measure known as Proposition 8, which outlawed same-sex marriage in spite of the fact that thousands of same-sex couples already had married during a brief period when their marriages were considered legal in the state.

The *New York Times* editorialized that one of the strongest points in Judge Vaughn R. Walker's historic decision was that traditional notions of marriage can no longer be used to justify discrimination. The judge wrote that all marriages are now unions of equals, and there is no reason to restrict that equality to heterosexual couples. Walker said California's ban on same-sex marriage violated the Fourteenth Amendment's rights to equal protection and due process of law.¹⁰¹² The case was considered likely to reach the U.S. Supreme Court. Andrew Koppelman, a professor at Northwestern Law School, said that "if the Supreme Court does not want to uphold same-sex marriage, its job has been made harder by this decision."¹⁰¹³ Erwin Chemerinsky, dean of the law school at the University of California–Irvine, said, "Federal judges are no longer persuaded that a moral condemnation of homosexuality justifies govern-

¹⁰¹². Unsigned editorial, "Marriage is a Constitutional Right," *New York Times* (4 August 2010).

¹⁰¹³. John Schwartz, "In Same-Sex Ruling, An Eye on the Supreme Court," *New York Times* (4 August 2010), 1.

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ment discrimination.¹⁰¹⁴

On June 24, 2011, New York became the sixth state to legalize same-sex marriage.¹⁰¹⁵ Joining Connecticut, Iowa, Massachusetts, New Hampshire, Vermont, and the District of Columbia, New York was by far the biggest political plum for the marriage-equality effort. Evan Wolfson, president of Freedom to Marry, a national group advocating for marriage equality, predicted the New York law would be a turning point in the effort to extend legal marriage to same-sex couples nationwide. “It means that the number of Americans living in a state where gay people share in the freedom to marry is more than doubling from 15 to 35 million.” What’s more, he added, “Because this is New York, people across the country and around the world are going to see and hear the stories that prove that families are helped and no one is hurt when marriage discrimination ends.”¹⁰¹⁶

Meanwhile, President Obama has continued to resist taking a firm position in support of same-sex marriage, coyly suggesting his views are “evolving.” The *New York Times* called Obama’s nebulous position “a straddle that will soon strain public patience.” As the paper put it, “Fundamental equality...is hardly the equivalent of a liquor law that can vary on opposite sides of

¹⁰¹⁴. John Schwartz, “Despite Setback, Gay Rights Move Forward,” *New York Times* (21 September 2010). At <http://www.nytimes.com/2010/09/22/us/22legal.html?hp>, accessed 22 September 2010.

¹⁰¹⁵. Phil Reese, “New York Approves Marriage Equality,” *Washington Blade* (24 June 2011).

¹⁰¹⁶. Phil Reese, “Advocates See New York as a Turning Point in Marriage Equality Effort,” *Washington Blade* (27 June 2011).

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a state line. Why is Mr. Obama so reluctant to say the words that could lend strength to a national effort now backed by a majority of Americans?”¹⁰¹⁷

Underscoring the fact that marriage equality is by no means the last barrier to full and equal participation of gay men and lesbians in American society, the *Los Angeles Times* editorialized, “[B]latant discrimination on the basis of sexual orientation remains permissible in workplaces across the nation, an injustice Congress must rectify.” The paper echoed the national gay and lesbian political groups in calling for passage of the Employment Non-Discrimination Act (ENDA), which would add inclusive language to the Civil Rights Act of 1964 prohibiting discrimination in public and private employment on the basis of “actual or perceived sexual orientation or gender identity.”¹⁰¹⁸

The same day as the L.A. *Times* editorial, another federal judge in California ruled the federal government’s “Don’t Ask, Don’t Tell” policy was an unconstitutional violation of gay and lesbian Americans’ First Amendment free speech and Fifth Amendment due process rights. Judge Virginia A. Phillips found the policy harmed military capabilities, hindered recruiting efforts, led to the discharge of “critical” service members, including medical professionals and Arabic and Persian linguists, and caused the military to enlist recruits whose criminal records, lack of education, or physical fitness would have otherwise dis-

¹⁰¹⁷. Unsigned editorial, “Gay Marriage: Where’s Mr. Obama?” *New York Times*, 26 June 2011.

¹⁰¹⁸. Unsigned editorial, “Protecting Gay Rights: Giving Federal Workplace Protection to Gay, Lesbian and Transgender Employees is a Necessary Step,” *Los Angeles Times* (9 September 2010).

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qualified them from service.¹⁰¹⁹

Even as we make progress toward legal equality in the United States, gay and bisexual men continue to be marginalized and persecuted around the world. It's not surprising to know we also continue to get short shrift in global AIDS conferences and programmatic priorities. The Joint United Nations Programme on HIV/AIDS (UNAIDS) estimates that, worldwide, fewer than one in twenty gay and bisexual men have access to HIV care, prevention, and treatment.¹⁰²⁰ Outside the United States, sex between men accounts for as much as 25 percent of all HIV infections in parts of Latin America, with rates nearly as high in Asia, and not as high in Africa where HIV much more strongly affects heterosexuals.¹⁰²¹

The International Lesbian, Gay, Bisexual, Trans and Inter-sex Association (ILGA) in 2010 reported that seventy-seven countries continue to outlaw same-sex relations, including five that impose the death penalty on citizens for being gay (Iran, Mauritania, Saudi Arabia, Sudan, and Yemen (plus some parts

¹⁰¹⁹. Phill Willon, "Federal Judge Rules 'Don't Ask, Don't Tell' Policy is Unconstitutional," *Los Angeles Times* (10 September 2010).

¹⁰²⁰. UNAIDS, *Global Initiative to Stop the Spread of HIV Among Men Who Have Sex with Men* (24 July 2007). At http://www.unaids.org:80/en/KnowledgeCentre/Resources/Feature-Stories/archive/2007/20070724_MSMinitiative.asp, accessed 15 September 2010.

¹⁰²¹. Avert.org, "HIV, AIDS, and Men Who Have Sex with Men." At <http://www.avert.org/men-sex-men.htm>, accessed 15 September 2010.

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of Nigeria and Somalia).¹⁰²² According to George Ayala, executive officer for the Global Forum on MSM and HIV (MSMGF), presentations addressing the HIV pandemic disproportionately affecting gay and bisexual men around the world accounted for a miniscule 2 percent of the entire program at the Eighteenth International AIDS Conference (called AIDS 2010) in Vienna. “That’s pitiful for an epidemic that is largely concentrated around men who have sex with men,” said Jim Pickett, advocacy director for the Chicago AIDS Foundation. “We have to do better.”¹⁰²³

We also have to do better in addressing HIV/AIDS in gay and bisexual men here in the United States. In August 2010, Duncan Osborne reported in *Gay City News* that New York City health department data indicate MSM in the city continue to have a very high rate of new HIV infection and efforts to get more HIV-positive men onto treatment may be failing. “Gay and bisexual men in New York City are continuing to get infected as the predominant transmission risk,” said M. Monica Sweeney, assistant commissioner of the health department’s HIV/AIDS bureau. The bureau reported that in 2008, 1,614 gay/bi men in the city were newly diagnosed as HIV-positive, further swelling

¹⁰²². Daniel Ottoson, *State-Sponsored Homophobia: A World Survey of Laws Prohibiting Same Sex Activity Between Consenting Adults* (The International Lesbian, Gay, Bisexual, Trans and Intersex Association: May 2010), at http://old.ilga.org/Statehomophobia/ILGA_State_Sponsored_Homophobia_2010.pdf, accessed 21 September 2010.

¹⁰²³. Rod McCullom, “AIDS 2010: Concerns for Black Gay and Bisexual Men Raised to National and Global Platforms,” *TheBody.com* (21 July 2010), at <http://www.thebody.com/content/confs/aids2010/art57632.html>, accessed 13 September 2010.

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the ranks of the 107,177 New Yorkers living with HIV through June 2009. As for preventing new infections, Sweeney said, “When it comes to the number of partners and how much sex gay men have, that’s not something that can be controlled by government. Those are things that community norms should do.”¹⁰²⁴

New York physician and Gay Men’s Health Crisis co-founder Larry Mass offered his own take on what GMHC is calling “an urgent priority,” the worsening HIV epidemic among gay and bisexual men in New York City.¹⁰²⁵ “There is no strong leadership voice out there,” said Mass, the world’s first chronicler of the AIDS plague in an interview not far from GMHC’s now-former home in Chelsea. “We don’t have a Larry Kramer out there.”¹⁰²⁶

Not long after our interview, Mass published a commentary in *Gay City News* offering his assessment of the current state of the HIV epidemic in gay America. “Taking a tougher stand on HIV transmission could blunt the re-escalating rates of infection in our community,” he wrote. While subway ads should continue showing happy bicyclists living well with HIV after getting tested and treated, Mass said we also need franker ones showing the

¹⁰²⁴. Duncan Osborne, “High Viral Load Suggests Gay Men Lagging on Treatment,” *Gay City News* (4–17 August 2010); New York City Department of Health and Mental Hygiene. *HIV Epidemiology & Field Services Semiannual Report* 5(1) (April 2010).

¹⁰²⁵. Gay Men’s Health Crisis (GMHC). *Gay Men and HIV: An Urgent Priority*. (New York: GMHC, 2010).

¹⁰²⁶. Lawrence D. Mass, MD, interview with author, New York City, 27 July 2010.

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potentially serious side effects and failures of treatment. He recommended a stronger 'HIV prevention consciousness' and believes regulation, ideally self-regulation, is needed in gay sex venues. Mass also suggested that educational posters about post-exposure prophylaxis, or PEP, would let gay men know that a thirty-day course of HAART has been shown to block HIV infection if begun within seventy-two hours of exposure. Mass said we need more public discussion and educational materials that raise the ethical issues about spreading HIV. "We need our current gay men's health crisis to be out in the open," he wrote, "warts and all, the way it was in the heyday of Larry Kramer's activism, however inconvenient that might seem given our current high-profile battles for equality." He added, "No, we are not dying in the thousands the way we were then, but we are still in real trouble with all this. Trying to stuff it back into the closet will eventually backfire."¹⁰²⁷

For his own part, Larry Kramer, at seventy-five, makes it clear he still has a clear mind and "tons of energy." These days, he chooses to focus it on the 2011 multiple Tony Award-nominated Broadway revival, and a forthcoming movie production, of his 1985 play *The Normal Heart*, about the early years of the AIDS epidemic in New York. As for his AIDS activism? The co-founder of GMHC and father of ACT UP, the man who became the angry voice of a gentle but frightened people in the darkest of the plague years, told me in his Washington Square apartment—a sacred space in gay American history—on a sweltering day in July 2010 that he'd recently had "a lot of interaction with Dr. Fauci." Kramer said he pushed his old nemesis, Anthony Fauci, long since a friend, to aim higher in the research he oversees as director of the National Institute of Allergy and Infectious Diseases (NIAID), to go for a cure.

¹⁰²⁷. Lawrence D. Mass, MD, "Gaining on Equality, Losing on Health," *Gay City News* (8 September 2010).

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Words matter for a man like Kramer, who has wielded them like a surgeon's scalpel, able to heal or cut to the quick as needed. He chooses his own words carefully, intentionally, in full consideration of their denotation and connotation. "I've been after him to use the word 'plague,'" said Kramer of Fauci. "It's a useful tool, it scares people." In fact, Kramer dared me to use 'plague' in this book "from beginning to end." A plague, he said, "is out of control, which it is."¹⁰²⁸

When I asked him about it, Fauci said, "I understand what Larry is getting at." He said he has used the word "plague" himself, depending on the audience and the point he wants to make. He said, "Larry wants to use the word plague because he wants to put it into the historical perspective of the handful of diseases throughout the history of mankind that had an enormous impact." Fauci said that when he talks about HIV to the White House or Congress or OMB (Office of Management and Budget) or constituencies, "I always put it in the context that we are living through a historic period from the standpoint of public health. There have only been a couple other periods where there have been such horrendous pandemics against the human population—bubonic, flu, smallpox."

As for a cure, Fauci said, "The numbers make it almost unfeasible to sustain a situation where you have 2.7 million getting newly infected every year." For every one person that receives HAART, two or three others get newly infected. "More people are getting infected than we are able to put on therapy," said Fauci.¹⁰²⁹ He said there are two choices: Do a better job

¹⁰²⁸. Larry Kramer, interview with author, New York City, 28 July 2010.

¹⁰²⁹. Anthony S. Fauci, MD, e-mail to author, 2 November 2010.

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with prevention, or “get to a point where you can get people off therapy.” As it is now, he said, we face “an economically unsustainable situation.”

There was a renewed push for a cure in the wake of stunning news from Berlin in 2006, that an HIV-positive American man also diagnosed with acute leukemia appears to have been cured of HIV infection. He was the beneficiary of a complex, expensive, and experimental stem cell transplant from a very rare donor with a genetic resistance to HIV infection found in only about 1 to 2 percent of white Americans and Western Europeans, about 4 percent of Scandinavians, and in no Africans, African-Americans, or Asians. The man’s leukemia was successfully treated after the donor cells essentially replaced his immune system. To everyone’s astonishment, the man also has remained HIV-negative since the procedure.¹⁰³⁰

Underscoring the exceptional nature of the so-called Berlin Patient’s experience, Fauci said the total eradication of HIV isn’t likely in the foreseeable future. “We have very good drugs that block HIV replication,” he said, “but we don’t have any drugs that can eliminate the virus from HIV-infected cells.” For this reason, he explained, “Getting an eradication cure will require fundamental science and discovery—which is truly unpredictable.”

On the other hand, there is what is called a “functional” cure. It likely would involve a sort of super dose of HAART, or another compound not yet known, to “smoke out” the latent virus that remains in the body. Virus drained from these so-

¹⁰³⁰. Bonnie Goldman, “The First Man to Be Cured of AIDS: An Update on the Amazing Story—This Month in HIV,” *TheBody.com* (September 2009), at <http://www.thebody.com/content/art53624.html>, accessed 27 September 2010.

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called reservoirs would then be dispatched with existing or adapted medication. Fauci said one of the greatest obstacles, even for a functional cure, is that HIV-positive individuals have to be treated early enough in their infection that they don't yet have reservoirs of virus. "The earlier you start therapy," he said, "the smaller is the reservoir of infection." He explained, "When you start earlier rather than late, you preserve HIV immune function. You bring the viral reservoir to such a small, miniscule segment so if you stop therapy, either with or without enhancing the immune system, you hope the immune system is able to rebound from its reservoir. That is a functional cure, because even though you haven't eliminated the virus from the body, you have a functional cure."

In 2010, NIAID announced a new \$42.5 million research initiative, dedicated to the memory of Project Inform founder Martin Delaney, who died in 2009 of liver cancer. The "Martin Delaney Collaboratory: Towards an HIV-1 Cure"¹⁰³¹ will support efforts to purge the reservoirs of HIV from the body and provide the functional cure Fauci described.

Of course receiving treatment is predicated on knowing one's HIV status. But in the US, with thousands of HIV-positive citizens already waiting to be accepted in the AIDS Drug Assistance Program, and others discouraged even from being tested, there is still a tremendous gap between what would be nice and what is. Fauci is diplomatic. "It's somewhat problematic at the domestic level," he said. "If you can't treat all the people who have advanced disease, how are you going to seek

¹⁰³¹. National Institute of Allergy and Infectious Disease, "NIH Solicits Public-Private Proposals for Research to Purge HIV Reservoirs," *NIAID Web Bulletin* (28 June 2010), at <http://www.niaid.nih.gov/news/newsreleases/2010/Pages/DelaneyRFA.aspx>, accessed 23 September 2010.

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and treat people who don't even know their HIV status?"¹⁰³²

Whether we call it a plague or pandemic, there are times it can, and does, seem HIV/AIDS is still out of control, still very much a crisis, even after thirty years. Just ask Lorri Jean. "I still think it feels like a crisis that 50 percent of African-American gay men are infected with HIV," Jean told me. She said it's "shocking and outrageous" that African-American gay and bisexual men in particular are so heavily affected by HIV, and that organizations in the gay community haven't seemed to care, judging by the agendas they set and the priorities they pursue.

Maybe her way of looking at things is shaped by the fact that a couple of floors below her office, the L.A. Gay and Lesbian Center's health clinic each month takes care of 2,500 people with HIV, and tests another 1,000 for the virus. Maybe it's the "throwaway" kids—mostly gay teenage boys, kicked out of or running away from their homes for being gay, at high risk for HIV infection from older men who promise love or pay them to have unprotected sex—in the center's homeless shelter a short elevator ride down from where she works. Maybe it's the center's HIV prevention programs that Jean said are being "eviscerated" by state and county funders. Or maybe it's that she simply hasn't forgotten the center's proud forty-year commitment to gay equality rooted in its founders' belief that only healthy, strong gay people can create and enjoy true gay liberation. No matter what it is, and no matter how you look at it, Lorri Jean said, simply, "We've reached a tipping point where there is harm to our community by people not realizing AIDS disproportionately affects our community."¹⁰³³

¹⁰³². Anthony Fauci, MD, telephone interview with author, 16 September 2010.

¹⁰³³. Jean interview.

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FORTY

Jim Beaudreau calls himself a “huge history buff.” He’d recently read a history of World War II before we met in San Francisco at the Fulton Street offices of the Gay and Lesbian Medical Association (GLMA), where he was education and policy director at the time of our interview in April 2010. Referring to the dark years of AIDS, in the eighties and early nineties, thirty-one-year-old Beaudreau sees gay men in their fifties—those who bore the brunt of the plague—as “a generation that went through what could be described in many ways as a war.” Like returning veterans of World War II, he said these men “don’t want to talk about their feelings and vulnerabilities.”

As for younger gay people, he told me, “It’s hard for people in my generation, in their twenties and thirties, to think of a time when people were dying, your friends, people you were close to.” Looking at old GLMA newsletters, he’s been struck by the fact that “they’re filled with obituaries of young physicians dying.”

I asked his thoughts about how to preserve the stories and legacies for our gay posterity and the world of our community’s extraordinary suffering and achievement in the AIDS years. How do we keep alive the memories of the men we’ve lost? Of AIDS organizations that began simply as friends and neighbors caring for one another? Of the focused rage and public relations brilliance that wrought changes in medical research and the drug approval process which benefit many beyond those with HIV? “Young people don’t want to hear about AIDS in San Francisco, and the magnitude of devastation that was going on,” said Beaudreau. “I haven’t talked to people who survived it

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in great detail. I imagine there's frustration that no one wants to hear about it."

In the seventies, just before San Francisco became ground zero in America's AIDS epidemic, the Castro district represented freedom for young gay men. Tens of thousands of them threw off the trammels of a disapproving society, left their oppressive small towns, and headed west. Many of them, like Harvey Milk, landed in the Castro. Many of them were young men, like Beaudreau. Half of them died from AIDS.

Today a young gay man like Massachusetts native Beaudreau tells a reporter, "My friends and I don't enjoy going out in the Castro because we'd rather not have our identities in San Francisco as being a gay man first." He explained, "If anything, I'd like my identity to be about a person who likes the outdoors, good books, and history. I generally don't have a good time hanging out in the Castro, which is like a meat market." Beaudreau nevertheless said he understands why people who feel unwelcome by their family, or like outcasts in their small towns, are drawn to the Castro even today. "You can imagine how amazing it must be to surround yourself with like-minded people who are in tune with you" he said.

I ask how GLMA, whose offices were formerly located in the Castro before relocating close to City Hall, keeps HIV/AIDS in focus. "Our job is to paint a fuller picture," said Beaudreau. "This isn't just about AIDS. This is about stigma and discrimination contributing to higher rates of anxiety and depression. Depression and anxiety contribute to substance abuse. Substance abuse can contribute to unsafe sexual practices and unwise decisionmaking." Beaudreau said GLMA also works to refute what he calls the "myth" of gay affluence. "Often in people's mind it's affluent white gay men in fancy sports cars, doing a lot of drugs, having unprotected sex. It can contribute to the idea

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that people deserve [AIDS]. We try to tread very carefully through that minefield and really reinforce the message that the rates of HIV in our community are due in large part to the fact that there has been a public disinvestment in public health campaigns and a lack of openness in high schools talking about HIV.” He said the recent ballot measures, such as California’s 2008 Proposition 8 banning same-sex marriage, “take a toll on LGBT people, especially young people, when they see this playing out.”

Beaudreau noted gay Americans’ successes in achieving some measures of equality, citing the gay political groups’ focus on marriage as a sign of a “maturing” movement. “Now that legal discrimination is coming to an end,” he said, “we have to address attitudes and stereotypes. We still need to do a lot of work to educate society at large that we are contributing members of society, come in all different shapes and sizes, that this is a very diverse community.”¹⁰³⁴

To the extent that public opinion polls represent anyone else’s opinion but the individual giving it, there has indeed been progress. Gallup reported in 2010 that Americans’ acceptance of “gay relations” had crossed what it called the symbolic threshold of 50 percent. Of course the term “relations” is usually used to describe sexual relations, which may explain why a slight majority (53 percent) of the 1,029 adults polled were still against legalizing same-sex marriage. Oddly, after decades of scientific studies and personal testimonials to the contrary, only 36 percent of those polled believe that homosexuality is a trait one is born with. The bottom line, said Gallup, is that “There is a gradual cultural shift under way in Americans’ views toward gay individuals and gay rights. While public attitudes haven’t

¹⁰³⁴. Jim Beaudreau, interview with author, San Francisco, 16 April 2010.

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moved consistently in gays' and lesbians' favor every year, the general trend is clearly in that direction."¹⁰³⁵

Gay people are more visible in the "mainstream" media—even if gay characters still account for minuscule percentages of the total number of regular characters on television. The Gay and Lesbian Alliance Against Defamation (GLAAD) reported in its annual survey *Where We Are On TV* that for the 2010–2011 broadcast television schedule, LGBT characters would account for 3.9 percent of all scripted series regular characters. This increase was actually more than three times the 1.1 percent they accounted for in 2007. Of the 587 series regular characters GLAAD counted across eighty-four programs on the five broadcast networks (ABC, CBS, The CW, Fox, and NBC), twenty-three were LGBT, an increase of five from eighteen LGBT characters counted in the previous year.¹⁰³⁶

Individual gay and lesbian stars shine brightly, and mostly openly, in the popular culture. Ellen DeGeneres, now hosts a popular daily talk show on NBC. In October 2010, Ellen spoke on her show with CNN news anchor Anderson Cooper about the recent rash of suicides among gay teenagers across the country. Fans openly celebrated Ellen's marriage to Portia di Rossi (now known as Portia Lee Jones DeGeneres, after a legal name change). Singer Ricky Martin outed himself. Suze

¹⁰³⁵. Gallup, "Americans' Acceptance of Gay Relations Crosses 50% Threshold" (24 May 2010). At <http://www.gallup.com/poll/135764/americans-acceptance-gay-relations-crosses-threshold.aspx>, accessed 17 September 2010.

¹⁰³⁶. Gay & Lesbian Alliance Against Defamation (GLAAD), *2010–2011 Where We Are On TV* (September 2010), at <http://www.glaad.org/document.doc?id=145>, accessed 30 September 2010.

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Orman advises Americans on their finances. Jane Lynch has redefined “tough-as-nails” as cheerleading coach Sue Sylvester on *Glee*. Comedian Wanda Sykes speaks openly about her wife. Cooper himself meanwhile has kept those for whom it apparently matters guessing his sexual orientation, piquing their prying minds by vacationing with another man believed (but not confirmed) to be his boyfriend. Shows like *Queer Eye for the Straight Guy* and *Project Runway* have become common reference points in pop culture. Although not gay herself, Lady Gaga in her short career so far has become a more famous and outspoken advocate for LGBT people than any gay man or lesbian.

Two of the last three presidents, President Bill Clinton and President Barack Obama, have recognized June as Lesbian, Gay, Bisexual, and Transgender Pride Month. President Obama stated in a June 1, 2009 proclamation, “Forty years ago, patrons and supporters of the Stonewall Inn in New York City resisted police harassment that had become all too common for members of the lesbian, gay, bisexual, and transgender (LGBT) community. Out of this resistance, the LGBT rights movement in America was born. During LGBT Pride Month, we commemorate the events of June 1969 and commit to achieving equal justice under law for LGBT Americans.”

Obama could be forgiven for inaccurately stating that the LGBT rights movement was born out of the Stonewall uprising; it had been going on for years before that June night in 1969. But his bold proclamation that LGBT people “have made, and continue to make, great and lasting contributions that continue to strengthen the fabric of American society” was precisely that, bold. Among our contributions to American society, Obama noted the fact that “LGBT Americans also mobilized the Nation to respond to the domestic HIV/AIDS epidemic and have played a

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vital role in broadening this country's response to the HIV pandemic."¹⁰³⁷

As same-sex-loving people have been brought further into the mainstream of American society, those living with HIV have also achieved a measure of progress toward equality in gay America. Still, offensive terms meant to exclude HIV-positive men as prospective partners—"clean" (vs. presumably "soiled" men with HIV) and "drug and disease-free," "DDF" for short—can be spotted in a striking number of gay male profiles in such popular online cruise sights as Craigslist, Manhunt, and Adam4Adam. Stigma is alive, thriving, and as invidious as ever in a community that worked so hard to diffuse and defeat it by insisting on terms like "person with AIDS" rather than "AIDS victim," "client" instead of "patient," "living with HIV" instead of "AIDS survivor." How we speak about HIV affects the way we think about it and view those who have it.

For those of us living with the virus, the language we use can have profound ramifications for how we view ourselves. For example, too many HIV-positive people refer to themselves this way: "I'm HIV." Of course they mean they have HIV, in the way someone with diabetes says, "I'm diabetic." But the implications of their literal words are unsettling. Gay people understood early in the epidemic that semantics matter in shaping both the public perception and personal understanding of what it means to live with HIV. This is why Frank Oldham, president of the National Association of People with AIDS, told me it's counterproductive to keep using the outdated, lifelong label of "AIDS."

¹⁰³⁷. Barack Obama, "Lesbian, Gay, Bisexual, and Transgender Pride Month, 2009," The White House: Office of the Press Secretary (1 June 2009). At http://www.whitehouse.gov/the_press_office/Presidential-Proclamation-LGBT-Pride-Month/, accessed 19 September 2010.

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Most AIDS diagnoses in the US today are based on a low CD4 (T-cell) count alone, with no opportunistic infection present. But even though the CD4 count typically rises to a normal level in most HIV-positive people receiving HAART, so long as they consistently take their antiretroviral medication, the Centers for Disease Control and Prevention still classifies them as having AIDS. I myself was diagnosed with a CD4 count of only 198. I knew it was considered an AIDS diagnosis. Until I researched the language of HIV disease, however, I didn't realize that despite 100 percent adherence to medication, regardless of a now-normal CD4 count and percentage (the percentage of white blood cells that are CD4s, considered a more reliable marker of immune function than always fluctuating CD4 counts), irrespective of never having had an opportunistic infection or other "AIDS-defining" condition beyond the once-low CD4 count, I am forever considered to "have AIDS."

Clearly the language of HIV hasn't kept pace with the reality of life for those of us living with the virus in the HAART era. Intended to be a clinical term, useful only in medical charts, the term AIDS carries a heavy burden of associations with images of disease and death. Said Oldham, "Telling people they have an AIDS diagnosis and will 'always have AIDS' is going to devastate the person emotionally. So you need to have language that encourages people to stay in treatment and shows they can get better."¹⁰³⁸

San Francisco HIV physician Christopher Hall said "the pervasive stigma" attached to the word AIDS makes him use the term as rarely as possible. He explained, "I feel I have to bring up the term AIDS out of necessity because it does persist as

¹⁰³⁸. Frank Oldham, telephone interview with author, 11 June 2009.

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relevant terminology clinically and epidemiologically.” But, he added, “I think it has become a vestige in the same way as GRID [Gay-Related Immune Deficiency, an early name for AIDS] was, because it was clearly stigmatizing. I think ‘AIDS’ is, too.”¹⁰³⁹ Regan Hoffman, the HIV-positive editor of *POZ* magazine, put it this way: “AIDS is a more frightening word than HIV. HIV is associated with a more modern era with people being able to be healthy on treatment.”¹⁰⁴⁰

Some in the HAART era find it disconcerting not to be able to “tell” that an individual has HIV. Unlike the early years, most gay men with HIV today can’t be identified by the purplish lesions of Kaposi’s sarcoma that truly were like stigmata marking the very faces of our fallen brothers. Tim’m T. West, program coordinator with the FUSION program at the St. Hope Foundation in Houston, told me young Black men who visit the drop-in center where he works have complained, “You make HIV look too good.” He laughed at the irony. “It’s like ‘how dare you look good,’” he said. “You should look frail and pale.”¹⁰⁴¹

Some people with HIV, including longtime activists, use medical procedures to erase, or at least temporarily mask, the potentially ravaging effects of lipodystrophy caused by years of toxic medication that rearranges body fat, including the fat beneath the face. Chemical fillers can restore confidence and allow a man not to confront his HIV status each time he looks in a

¹⁰³⁹. Christopher D. Hall, MD, telephone interview with author, 11 June 2009.

¹⁰⁴⁰. Regan Hoffman, telephone interview with author, 11 June 2009.

¹⁰⁴¹. Tim’m T. West, telephone interview with author, 21 July 2010.

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mirror or sees others' shocked look at his own gaunt appearance. Not looking the part of "person with AIDS," HIV-positive people managing their infection with appropriate medication can be freer to integrate what they think and feel about having HIV with their other sources of personal identity. Mark S. King described his own experience. "When I had facial wasting—I was beginning to have 'the look,' and after twenty-something years in the field, doing interviews, wearing that teeshirt ("HIV-positive")—suddenly I didn't have a choice in terms of people looking at me. It wasn't so much fun anymore. I couldn't say, 'Surprise! I'm HIV-positive!'" He said he learned "that label does mean something to me when it's involuntary." He added, "It's easy being an HIV poster child when it looks like you don't have it."¹⁰⁴²

In the early years of AIDS, gay men with HIV considered it a brave and obligatory act of courage and solidarity to "come out" as HIV-positive. It mattered both politically and medically, as it helped to destigmatize HIV by forcing a fearful public to confront actual people rather than "a virus," and scientists to see human faces instead of "transmission categories." But today, silence about having HIV is the preferred option of gay men who don't want to be identified based on their HIV status. "Back in the eighties," recalled veteran New York gay activist, author, and now retired English professor Arnie Kantrowitz, "it was like being gay, a political thing, which ACT UP helped to foster. And being visible helped the rest of the world to see how widespread the epidemic was and to see that there was a minority group that wanted its rights, even though they were based on medical issues rather than other issues. So it was helpful to teach that lesson. Now that it's been curtailed and accepted to a large degree, there is less reason to announce yourself."

¹⁰⁴². Mark S. King, Skype interview with author, 29 April 2010.

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Kantrowitz described his own experience of coming out as gay to his students. “When I first came out to my students as gay it was a big shock,” he said. “I started doing that in 1970, before it was very fashionable. Students had to write about it, they had to comment on it, ask questions. As the years went on, I made a point for my political reasons to come out to all my classes. I taught for another thirty-six years.” He added, “You could just watch each successive generation of students changing so that they don’t understand what’s the big deal, why do you have to tell us—because they take it as part of the natural landscape, you see. I answered that some of you are me, and you need to know that it’s ok, that you can not only survive but flourish being gay.” Kantrowitz concluded, “I think telling people you’re a PWA [person with AIDS] may be parallel, but there’s a lot to be said for minding your own business.” For himself, as one of the millions of Americans living with a chronic illness, he said, “I’m not entirely comfortable telling people I have diabetes. I’m not a ‘patient.’”¹⁰⁴³

If you have any doubt that HIV has been downgraded from community rallying cry to mind-your-own-business, talk to Pat Hawkins. As a lesbian and psychologist she has worked professionally from the earliest years of the AIDS epidemic with Washington, D.C.’s Whitman-Walker Clinic and other HIV organizations. The early spring afternoon of our interview in Washington, Hawkins was wearing another of her hats, with The Center, D.C.’s LGBT community center. Hawkins recalled the days when gay men came out with AIDS as they had come out as gay—their bravery, political daring, liberation and trepidation,

¹⁰⁴³. Arnold Kantrowitz, interview with author, Old Saybrook, Conn., 27 June 2010.

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the community's embracing support. By contrast Hawkins said today, "Even HIV-positive guys aren't out to each other."¹⁰⁴⁴

From the early years of AIDS, people living with the virus have been the best advocates for their own needs as well as the needs of the service organizations created to serve them. But between white gay men proclaiming the end of the AIDS crisis because of their personal good experience with HAART, and HIV-positive men not even "outing" themselves to one another, stigma and the ignorance that fuels it gains traction.

The Kaiser Family Foundation reported in 2009 that as many as a third of young people ages eighteen to twenty nine believed incorrectly that HIV could be transmitted through sharing a drinking glass, touching a toilet seat, or swimming in a pool with someone who is HIV-positive.¹⁰⁴⁵ Three decades into a still-deadly epidemic, and a third of American young people can't even identify the most basic facts about HIV transmission. As Americans check HIV off their list of pressing concerns, young people remain as uneducated as ever about how the virus is and is not transmitted. Middle-class gay men with HIV seek their medical care from private physicians. And AIDS service organizations (ASOs) across the country are struggling to stay relevant and raise the funds they need to keep serving people with HIV. As in past years, large numbers of their clients are men who have sex with men. But now they are largely neither white nor middle class.

¹⁰⁴⁴. Patricia D. Hawkins, interview with author, Washington, D.C., 25 March 2010.

¹⁰⁴⁵. Kaiser Family Foundation, *2009 Survey of Americans on HIV/AIDS: Summary of Findings on the Domestic Epidemic*, at <http://www.kff.org/kaiserpolls/upload/7889.pdf>, accessed 7 October 2010.

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New London, Connecticut-based Alliance for Living traces its roots to 1986, when a group of volunteers concerned about the lack of services for area residents living with HIV formed the Southeastern Connecticut AIDS Project. With a blend of professionals and volunteers, the project offered counseling, advocacy, housing assistance, transportation, community meals, support groups, and access to nutritional and therapeutic programs. I myself have been one of Alliance's current 275 "members" since I relocated to the area in 2007. Alliance's then-director Sandra Brindamour told me in 2010 that, like other early AIDS organizations, Alliance began as a project whose "basic mission was to help people die with dignity because there was no recourse at the time." Back then, she said, most members were white gay men. Today's gay clients are typically men who were employed and had health insurance through their jobs, then lost the jobs in the recession. Besides these men, she said the agency is seeing more women who have been infected by a boyfriend or husband who is either bisexual or injects drugs. The common denominator among them all: low income.¹⁰⁴⁶

In fact, many of the non-medical challenges facing greater numbers of people with HIV are often no different from others dealing with addiction, mental illness, and poverty. And as more of us are able to live well with the virus, and fewer define ourselves by our HIV status, it has become more challenging for the organizations that serve us to hold onto their claim of providing unique services unavailable anywhere else.

From her catbird seat in Hartford, Shawn Lang sees challenging times ahead for AIDS service organizations. "The writing is on the wall for stand-alone ASOs," she told me. She said

¹⁰⁴⁶. Sandra Brindamour, interview with author, New London, Conn., 30 April 2010.

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the groups need to be competitive if they want to continue. One way is to diversify their funding by branching out to offer their services, such as housing assistance, to others besides people with HIV. To now, Lang said dedicated service agencies for people with HIV have been able to articulate why they are needed. But the ability to manage HIV with medication has made the case for the single-disease organizations harder to make.¹⁰⁴⁷

Boston's AIDS Action Committee had just merged with Cambridge Cares about AIDS weeks before I interviewed AIDS Action's executive director Rebecca Haag in July 2010. The larger AIDS Action, with an annual budget of nearly \$10 million and the smaller \$3 million organization across the Charles River wanted to reduce costs and give clients the option to use either or both agencies' services without needing to do two separate intakes. "This is fundamentally about being better positioned to serve our clients," said John Gatto, now senior vice president of programs for AIDS Action but formerly the executive director of CCA in a news release. "By merging, we have eliminated redundancies, reduced administrative expenses, and freed up resources for services."¹⁰⁴⁸

In the early years of the epidemic, Haag said, the harsh stigma and discrimination against people with HIV required building strong "vertical" organizations like AIDS Action Com-

¹⁰⁴⁷. Shawn Lang, interview with author, Hartford, Conn., 6 July 2010.

¹⁰⁴⁸. John Gatto, quoted in "AIDS Action Committee of Massachusetts and Cambridge Cares About AIDS to Merge," (News release, 1 July 2010), at http://www.aac.org/site/News2?news_iv_ctrl=-1&page=NewsArticle&id=20509, accessed 27 September 2010.

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mittee. “We had to do it all,” she said. AIDS Action’s services, typical of many large ASOs across the country, included legal services (particularly wills and powers of attorney); prevention education programs; a meal program; a housing program; and a hospice program. Now, said Haag, there’s a trend of ASOs becoming more “horizontal” by expanding their mission to serve other populations besides only people with HIV/AIDS. “There’s a recognition that somebody doesn’t need housing because they’re HIV-positive,” she said, “but because they’re poor or are disabled and have AIDS.” She said the unanswered question today is how to maintain a separate delivery system when the needs of your people are no different from those of others.

Haag said that funding cuts, especially in the recent recessionary years, could mean the days of stand-alone organizations “may be waning.” But she added, “Our mandate is to fulfill our mission, not to make sure our organization exists.” She said this might mean that in coming years the services now provided by a big ASO like hers may be provided by smaller organizations. She was clear, however, that for AIDS Action’s twenty-one hundred clients, addressing their medical needs is just the starting point.

Massachusetts makes it easier for a person with HIV and low income to access medical care, said Haag. She pointed out that four in ten people with HIV in the US receive their medical care paid for through the federal-state Medicaid program. Most of those who qualify have low income and are considered disabled.¹⁰⁴⁹ “At least from a medical point of view,” said Haag, “somebody in Massachusetts technically does have access to care and treatment and drugs they need.” But, Haag told me, the barriers facing many AIDS Action clients go beyond their

¹⁰⁴⁹. Kaiser Family Foundation, *HIV/AIDS Policy Fact Sheet: Medicaid and HIV/AIDS* (February 2009).

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physical health to the drivers that motivate and shape actions and choices. These include homophobia, substance abuse, poverty, or a perception that the medical community is unfriendly to immigrants or Black people. Whether real or perceived, even the difference between feeling welcomed or “tolerated” can affect how people think about going to a place that may be their only gateway to programs that can help them stay well, such as the AIDS Drug Assistance Program. There are other potential obstacles to accessing and adhering to treatment. “Just having access to health care doesn’t mean you’re going to stay healthy if you don’t have transportation to your medical appointments,” said Haag.

The agency still serves middle-class gay male clients who mainly take advantage of its support groups. But more typically it sees young gay men of color who come to MALE Support, AIDS Action’s drop-in community center. “We’re helping them get into the community and find jobs,” said Haag. “Some of them are homeless, sleeping on people’s couches. Some are exchanging sex for drugs.” In fact, she said, “the issue that is most challenging now is the need for job training, skills, and education.” Haag said AIDS Action is working with other agencies that provide job training.¹⁰⁵⁰

AIDS Action’s experience of merging with Cambridge Cares is unusual for AIDS service organizations. Resentment and rivalry among agencies has been more typical, often fanned by funders who expect the agencies they support to be more comprehensive rather than specialized in the services they offer. It’s a common experience in the HIV services world: Community programs that are pioneers in serving their respective constituents (gay men, for example), or providing particular ser-

¹⁰⁵⁰. Rebecca Haag, telephone interview with author, 20 July 2010.

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vices, are forced to compete for funding by serving other populations or adding on more services just to win a contract.

After working for twenty-five years with AIDS service organizations across the country, National Minority AIDS Council director Paul Kawata in 2010 described what he called “the *Darwinization* [Kawata’s italics] of AIDS service organizations.” One of the last remaining “first generation” national AIDS organization directors who began working in the epidemic’s early years, Kawata believes the future of the “movement” will be decided by federal, state, local, corporate, and foundation funders, and a shrinking pool of individual donors. “The new reality,” he said, “means that either you get the grant and stay open or you close your doors. There are very few new funding options.” Kawata predicted that small and rural cities would eventually have, at most, one ASO whose services will be coordinated with its local health department and other nonprofits. Each year its budget will decrease as state and local government reduce or flat-fund their HIV commitments. In some communities, services will move to the local health department as ASOs close their doors. In bigger cities, there will be more than one ASO. But “even in these environments,” wrote Kawata, “you are seeing a culling of the field.”¹⁰⁵¹

I asked Kawata in an interview if there are opportunities for agencies to merge or at least work together, like AIDS Action Committee and Cambridge Cares. “In the majority of the organizations I speak with,” he said, “merger is not an option. There is so much animosity out there, bad blood, ill will, that people would rather close their organizations than merge.” But if the

¹⁰⁵¹. Paul Akio Kawata, “NMAC’s ED Reflects on the Future of HIV/AIDS Activism in the US,” National Minority AIDS Council (2 March 2010). At <https://nmac.org/index/news-app/story.358>, accessed 21 September 2010.

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organizations allow their self-preservation and turf wars to keep them from thinking of their clients'—rather than their own—greater good, Kawata said, “Funders are going to make decisions about who survives and who closes their doors.” He added, “I don’t think funders want to make this decision. But you have to focus your money.”¹⁰⁵²

Black AIDS Institute director Phill Wilson said, “It doesn’t make sense, and it is increasingly unsustainable, to have parallel health delivery systems.” He said two things have happened, both of them good in his view, as the epidemic has changed in this country. “There is mainstreaming, so organizations that deal with child welfare can address the issues of children with HIV. Organizations that are dealing with mental health or youth can address HIV in the context of their missions.” He said the HIV-focused groups now understand the relationship between HIV and STDs, mental health, and addiction, and are expanding their services accordingly. “Even if AIDS is the engine of their work,” he said, “the movement is away from institutions focusing only on AIDS and probably that’s a good thing.”¹⁰⁵³

Not far from the Black AIDS Institute’s offices on West Eighth Street in downtown Los Angeles, the Minority AIDS Project serves the largely Latino and African-American residents of South Central Los Angeles from its offices on West Jefferson Boulevard. Founded by the Reverend Carl Bean as a mission of his LGBT-oriented Unity Fellowship Church, the agency has been a neighborhood presence and lifeline since 1985. On the morning I visited, a Latino man arrived just after

¹⁰⁵². Paul Akio Kawata, telephone interview with author, 17 September 2010.

¹⁰⁵³. Wilson interview.

VICTORY DEFERRED

me for a rapid HIV test. A transsexual African-American woman assisted him with check-in.

Rev. Russell Thornhill, now-Archbishop Bean's assistant pastor at Unity Fellowship and MAP's program manager, sees the belt-tightening and streamlining as an opportunity for ASOs and other community organizations to cooperate as part of a network, or continuum of care, that requires working together rather than each agency trying to "do it all." Thornhill said collaboration like this could be done in either a positive or negative way. "One comes forth with honesty and integrity, and says, 'I really want to be able to work with you. How can we work together? Is there something that we can do together? Is there a service that we have that you don't have? Is there something that we can provide that you're not able to provide so we can work on this together?'"

On the other hand, said Thornhill, it's "a negative collaboration when people just move in and say, after the fact, 'Ok, I'm here and I have this to help you, what can you help me with?'" The latter approach isn't collaboration, he said; "You're just encroaching on our area." Funders want to see more linkages, rather than fewer, said Thornhill. And there is more than ample opportunity for service providers to link with others. In an area like South Los Angeles, with hundreds of thousands of residents, he said, "There's so much in the community that there is probably enough room for all the folks who want to come into collaboration. You could have just one organization that works on housing developments, and that's just in South Central." He said there are also treatment centers, halfway houses, post-incarceration locations, and a plethora of other needs that represent opportunities to serve the people of the area. "Take off that adversarial hat," said Thornhill, "and just take a look at 'What can I put on my plate to work on, based on the money I'm getting? What am I able to do? Let me do that and do it well.'" On

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the other hand, he said, “If I put on my adversarial hat and fight you because I don’t want you to come into the community, then ok, maybe you don’t come into the community, but I’m not able to provide all the services because I don’t have the funding. So who gets hurt in the end? The people get hurt in the end.”¹⁰⁵⁴

Before anyone dismisses AIDS service organizations as relics of an earlier, desperate time when mega-agencies had to do everything, a bit of perspective is called for. So is a reality check as to whom, exactly, the organizations have been serving for years and why they still have a vital role to play. Terje Anderson brings an unusually broad perspective to the subject. A former director of the National Association of People with AIDS, he spent eight years as director of the Southern Colorado AIDS Project, and was Vermont’s statewide AIDS program director. He is also living with HIV. “Let’s remember why stand-alone AIDS service organizations were created in the first place,” he said in an interview. “It was because the rest of the system could not meet the needs of people living with HIV/AIDS.”

Anderson said it’s important to realize the disappearance of ASOs will not come about because their services are no longer needed. “A lot of the services are just going to go away,” he said. “Maybe that’s ok. Maybe a large block don’t need services that were useful fifteen years ago. But I think there are going to be a lot of people falling through the cracks who are poured out of the system.” Anderson described a friend whom he said probably could have been on disability a few years ago, but who didn’t understand the application process. Now he’s on the verge of losing his house. There was no nearby ASO where a case manager could help the man sort out the applications and

¹⁰⁵⁴. Rev. Russell Thornhill, interview with author, Los Angeles, 12 April 2010.

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other requirements for accessing programs that might assist him. Without ASOs to provide points of access for people with HIV, said Anderson, “There’s not going to be that coordination of care, that system, that at least tried to make things work for people. And that’s going to be really problematic.”

Today, said Anderson, living with HIV has been largely reduced in the minds of those who don’t live with the virus, often including service providers who aren’t HIV-positive themselves, to a “mere” medical issue. “We used to look at HIV/AIDS as a multi-prong issue,” he said, “not just a medical issue. It was also political, equal rights, very much connected with gay identity. More and more of that has been leached away. More and more we are coming back to ‘It’s just about medical, health care.’ All these other ‘pieces’ have lost their oomph; they’re not part of the picture.” He added, “This is a double-edge sword. Now it’s about ‘Take your medicine and you’ll be fine.’ There’s not an understanding about how profoundly [having HIV] can affect your self-identity. There’s not the level of support or understanding that there used to be of how complex it is, how much it does impact your life. It used to be there. Now people just shrug it off.”¹⁰⁵⁵

At Miami’s Care Resource, director Rick Siclari told me, “Medical care is at the center of our ‘Center of Excellence,’” as the federal government classifies model health care centers, so-called “medical homes.” He added, “Even in the late nineties it was becoming clear that treatments were here and would be at the core of everything we do about HIV. But we still need wraparound services.”¹⁰⁵⁶ The agency expanded its services

¹⁰⁵⁵. Terje Anderson, telephone interview with author, 22 September 2010.

¹⁰⁵⁶. Siclari interview.

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beyond HIV/AIDS, though comprehensive HIV care is still an important part of its work.

Other LGBT community health centers across the country have likewise broadened their focus. Some, such as Boston's Fenway Health, have had an easier time maintaining their identities as health centers rather than as AIDS service organizations because of decisions made early in the epidemic. AIDS Action Committee, New England's first and largest ASO, started out in 1983 as a Fenway committee whose members wanted a freestanding agency that could do advocacy and educational work. Others, such as Washington, D.C.'s Whitman-Walker Clinic, have had a harder time returning to their roots as LGBT health centers after years of being seen primarily as AIDS service organizations.

Fenway Health president and chief executive officer Stephen L. Boswell told me the "crisis sense" about HIV brought the organization critical resources that enabled it to build the infrastructure that today lets it focus on broader LGBT and other community health issues. When effective HIV treatment allowed a respite from the death and dying, Boswell said the agency revisited its mission. "When the AIDS epidemic started to become a manageable disease," he said, "I remember deliberately thinking it's time for us to take a breath and think about what we're doing, what we want to be doing, who we are. We wanted a larger mission than just HIV/AIDS." He praised Fenway's board for the decisions it made in the nineties and throughout the last decade. Said Boswell, "It's managed to maintain its identity as a community health center that serves not just the LGBT community, but the neighborhood."¹⁰⁵⁷

¹⁰⁵⁷. Stephen Boswell, MD, interview with author, Boston, 24 June 2010.

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Boswell also noted Fenway's role as a federally supported research center, and its widely circulated *Fenway Guide to LGBT Health*, a comprehensive book written by leading clinicians offering practical guidelines and discussions of clinical issues relevant to the LGBT population. Serving thirteen thousand patients, including fourteen hundred HIV-positive individuals, from its new ten-story, \$60 million, 100,000-square foot building ("the largest building ever constructed by an organization with a specific mission to serve the LGBT community," states its website¹⁰⁵⁸), fueled by a \$41 million budget, Fenway is also active in shaping the future of care for LGBT people. The agency regularly trains medical service providers on the "Fenway Community Health Model"¹⁰⁵⁹ of culturally competent care for LGBT patients.

Much like the continuum of care, the network of coordinated community-based services, that San Francisco pioneered in the eighties (known as the "San Francisco model"), and that AIDS service organizations replicated, Fenway offers medical services, including comprehensive HIV care; mental health, addiction, and wellness services; and community education services—all under one roof. The Fenway Institute, the agency's research division, has already generated hundreds of peer-reviewed articles based on research conducted at Fenway. The agency has become a model for other community-health organizations that want to provide the best care possible to their

¹⁰⁵⁸. Fenway Health, *2009 Annual Report*, at <http://www.fenwayhealthannualreport.org/aboutfenwayhealth.html>, accessed 28 September 2010.

¹⁰⁵⁹. Kenneth Mayer, Jonathan Applebaum, Tracey Rogers, Wilson Lo, Judith Bradford, Stephen Boswell, "The Evolution of the Fenway Community Health Model," *American Journal of Public Health* 91(6), (June 2001): 892–894.

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LGBT clients. Its view of what that care looks like lies in what Fenway Institute medical research director Ken Mayer called the agency's "broader vision of health."¹⁰⁶⁰ This broader vision of health, and the "medical home" style of one-stop-shopping for medical services that Fenway offers, is supported in the Obama administration's 2010 National HIV/AIDS Strategy for the United States. The Institute of Medicine has said this "patient-centered care" should be the standard for all Americans.¹⁰⁶¹

Washington, D.C.'s Whitman-Walker Clinic has had a harder time of reclaiming its pre-AIDS identity as an LGBT health center rather than being mainly an AIDS service organization. Executive director Don Blanchon enumerated the difficulties, some of them self-inflicted, that kept the clinic from evolving beyond its role as an "AIDS organization" as soon as it probably should have done. Just as medical treatment in the mid-nineties was beginning to transform HIV into a chronic, manageable condition—with profound implications for the clinic's future—longtime director Jim Graham left to run for the D.C. city council. While other gay and lesbian health centers around the country looked to Whitman-Walker—for years one of the nation's leading AIDS service providers—to join them in broadening their scope beyond HIV/AIDS, the clinic chose to remain an ASO, probably "unknowingly" for financial reasons, said Blanchon. AIDS is where the funding was, after all.

¹⁰⁶⁰. Kenneth H. Mayer, M.D., interview with author, Providence, R.I., 9 April 2010.

¹⁰⁶¹. The White House, Office of National HIV/AIDS Policy, *A National HIV/AIDS Strategy for the United States* (July 2010), at <http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf>, accessed 7 October 2010.

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Things continued to change, raising doubts about the clinic's decision to stay focused on HIV/AIDS. HIV care shifted away from the kinds of ancillary and palliative services ASOs traditionally provided to being more about medical care. Middle-class gay men who had formerly been Whitman-Walker clients could now get their HIV medical services in private doctors' offices paid for by private health insurance. Charitable donations of all sorts plummeted in America after the terrorist attacks of 11 September 2001, and with them contributions to the clinic's annual fundraising AIDS walk also declined (netting only \$4,000 in 2001, and \$100,000 in 2002—from a peak of \$1.7 million in 1997).¹⁰⁶² The city moved all its Medicaid patients into managed care and changed the way it bought HIV medications. This meant Whitman-Walker could no longer add even a modest mark-up to the pharmaceutical prices they charged patients to recoup a bit more of what it cost them for their services. In late 2004 a financial scandal erupted when the clinic self-reported that it had been overbilling the Ryan White program for lab costs to the tune of \$2.5 million over three years. The clinic started using assets people had left it in their wills to finance operating costs. It missed payroll in May 2005. It faced a financial meltdown of the first order. Said Blanchon, "It's been a whirlwind ever since."

The winds of change appear to be whipping the clinic back on course, if significantly reduced in size, toward being the LGBT health center it might have become before AIDS inundated and redefined it in the eighties. Blanchon said Whitman-Walker is seeking to live into its original mission as a gay and lesbian health center; neither defined by nor limited to its HIV/AIDS services. "We will serve our neighborhood," Blanchon

¹⁰⁶² Carol Morello, "DC Clinic Reevaluates AIDS Walk: Revenue Down Sharply for Fundraising Event," *Washington Blade* (24 October 2002), B1.

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told me. “We will serve people living with HIV regardless of their orientation or identity. But by and large we are trying to create a high quality health center for the LGBT community because that’s what our articles of incorporation said, that’s what the community needs based on what we know about health disparities, and, quite frankly, that is the most sustainable business model the clinic can pursue.” Transforming the organization from an ASO to a health center, said Blanchon, “is nothing short of painful.” He said it requires “exponential change” including changes in board, staff, systems, IT, phones, medical records, and third-party billing. Not only that, but he added, “There are people who don’t like what we’re doing. They’re pissed off at Whitman-Walker for things that happened ten or twenty years ago.” Blanchon said some, mainly older gay men, feel territorial about the clinic, saying things like “The clinic is ours, we built it.”

Having reported on the clinic’s evolution since the mid-1980s, when it occupied a tiny two-room suite in the Adams-Morgan neighborhood, I can attest to the truth of Blanchon’s words. I also witnessed how the white gay men who “built” the clinic with their donations and volunteer labor resented the clinic’s efforts to become “professional” in the late eighties. In the nineties, they resented the clinic’s expansion to serve other people, especially low-income people of color. Perhaps they didn’t understand that the clinic was required, like every other community agency receiving much-needed federal Ryan White CARE Act funds, to serve anyone who needed its services. Now they resent the clinic’s latest shift away from its principal identity as D.C.’s chief AIDS organization.

Blanchon is resigned to not pleasing everyone. He sees the clinic’s future in serving younger LGBT people. He believes they will appreciate what Whitman-Walker is seeking to provide. The clinic’s latest reinvention will not carry for them the painful

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associations it carries for many older men whose departed friends and lovers the clinic cared for. “I think our future is really the next generation of LGBT community members,” said Blanchon, who is not gay himself but whose brother died from AIDS. “We want to brand the clinic as saying ‘Come here and get your medical care, we’re in your area, we’re a readily accessible, affirming place where you don’t have to worry about your orientation.’”¹⁰⁶³

¹⁰⁶³. Donald Blanchon, interview with author, Washington, DC, 25 March 2010.

FORTY-ONE

When the late 1990s Urban Men's Health Study investigated a set of health conditions (including HIV risk, substance abuse, depression, partner violence, and suicidality) among American gay and bisexual men in large cities, it became apparent that many of the most prevalent and deadly health conditions were linked. Medical anthropologist Ron Stall and his colleagues said urban gay and bisexual men have a high prevalence of at least four interconnected "epidemics" of psychosocial health conditions. Each makes the others worse: childhood sexual abuse, partner violence, depression, and drug use. Together, their insidious effects are referred to as "syndemics." Men who are most strongly affected by any one of these also tend to be at high risk for HIV transmission or infection. Gay and bisexual men from lower income or culturally marginalized ethnic groups are especially vulnerable to syndemic effects.¹⁰⁶⁴

Stall, together with colleagues Mark Friedman and Joseph A. Catania, says that challenges to gay men's health begin early in life, when young gay boys are punished in socially shaming ways for straying from the masculine gender role expected of us. This "masculinity panic" can profoundly wound young males, worst of all when parents are the source of the put-

¹⁰⁶⁴. R. Stall, T.C. Mills, J. Williamson, T. Hart, C. Greenwood, J.P. Paul, et al. "Association of Co-Occurring Psychosocial Health Problems and Increased Vulnerability to HIV/AIDS Among Urban Men Who Have Sex With Men," *American Journal of Public Health* 93(6) (2003):939–942.

VICTORY DEFERRED

downs and pressure to conform to the supposed manly ideal. The researchers note there can be even more confusion and challenge for young gay men who move to urban gay ghettos seeking a community of like-minded individuals. While it's true they are likely to find support and resources they wouldn't have had in their hometowns, they also encounter other potential stressors as they seek to find their place in the gay community and in the world. For example, the high cost of living in major cities can make home ownership impossible, adding to the feeling of not living up to imposed expectations brought from childhood, and triggering psychosocial problems and high risk behavior, such as drug abuse and unsafe sex.¹⁰⁶⁵

Stall explained in an interview why the syndemics concept is useful for recognizing connections between seemingly disparate behaviors, such as smoking and HIV risk. "When you take a syndemic approach," he said, "people who are marginalized from an early age are maybe more likely to pick up smoking during their adolescent years and engage in personal worth-affirming behavior." He likened the situation to soldiers taking up smoking in wartime. "For gay men whose lives are like battles," he said, noting the unusually high rate of smoking among LGBT people, "maybe cigarettes aren't a surprising escape."

The challenge for health care providers and HIV prevention researchers, said Stall, is to find ways to disrupt the destructive processes that contribute to the formation of self-destructive

¹⁰⁶⁵. Ron Stall, Mark Friedman, Joseph A. Catania, "Interacting Epidemics and Gay Men's Health: A Theory of Syndemic Production Among Urban Gay Men." In Richard J. Wolitski, Ron Stall, Ronald O. Valdiserri (eds.), *Unequal Opportunity: Health Disparities Affecting Gay and Bisexual Men in the United States* (New York: Oxford University Press, 2008), 251–274.

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gay men. He said health disparities are in place by age eighteen. “Something horrible is happening during adolescence to young gay men,” said Stall. “These young men don’t understand what’s happening to themselves. There’s no community. Sometimes if the sissy boy goes to dad to tell about getting beat up on the playground, he risks being beaten up by his dad. That kind of experience has got to be searing, and leaves scars on gay men. They learn at a tender age not to step out of gender lines or they will get the shit kicked out of them.” He added, “If you treated an adult the way a lot of sissy boys are treated in school yards, you would get arrested.”¹⁰⁶⁶

Caitlin Ryan is, by anyone’s reckoning, among the founding mothers of the gay and lesbian health movement that began in the 1970s. Perhaps it’s a maternal instinct to protect the young and vulnerable, or the Catholic’s mission to heal the world she was raised to pursue, which drives Ryan’s concern about the health of sexual minority youth. From her academic base at San Francisco State University, Ryan’s research on the role of families in shaping the health of young lesbian, gay, and bisexual adults has rattled the field of pediatrics—and the minds of many parents who have treated their son or daughter with condemnation and rejection. Her study was the first to show a link between a young LGBT person’s health and their home life. One of the more startling findings in the research Ryan published in *Pediatrics*, the influential journal of the American Academy of Pediatrics, was that “families that try to hold back an LGBT kid from ‘being gay’ have the same effect as beating,” as she put it in an interview.

Ryan found that young adults whose families strongly rejected them were 8.4 times more likely to report having attempted suicide, 5.9 times more likely to have depression, 3.4

¹⁰⁶⁶. Ron Stall, telephone interview with author, 8 June 2010.

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times more likely to use illegal drugs, and 3.4 times more likely to report having engaged in unprotected sexual intercourse compared with peers from families that reported little or no negative reactions to their sexual orientation in adolescence. Latino men fared worst, reporting the highest number of negative family reactions.¹⁰⁶⁷

Ryan said she has worked with parent-teacher associations in Massachusetts, county school systems in California, Mormons, evangelicals, and ethnic community organizations to spread the word that parents—even those who are uncomfortable with the thought of having a gay child—can make the difference between a healthy young adult and one who is more prone to mental health challenges and risky behavior, possibly even suicide. Working with families and others responsible for educating and “forming” young people, Ryan told me she sees many parents shocked to realize the impact of their rejection. “We have had people in tears when they realize the harm they have done to their children,” she said. “They actually don’t want their children to die from suicide. It’s important to give young people a sense that life is worth living.” Referring to the implications of her work for HIV prevention efforts, Ryan said, “I’m going beyond putting a condom on someone’s penis.” She said that applying her research findings to the development of new HIV prevention programming “would change the future as far as HIV prevention for young people.”¹⁰⁶⁸

¹⁰⁶⁷. Caitlin Ryan, David Huebner, Rafael M. Diaz, Jorge Sanchez, “Family Rejection as a Predictor of Negative Health Outcomes in White and Latino Lesbian, Gay, and Bisexual Young Adults,” *Pediatrics* 123 (2009):346–352.

¹⁰⁶⁸. Caitlin Conor Ryan, telephone interview with author, 18 April 2010.

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For three decades, HIV prevention efforts targeting gay and bisexual men have constantly run aground on the abundance of attitudes and behaviors among these men that can impair someone's ability to make clear, healthy choices. At Houston's St. Hope Foundation Tim'm T. West said the young men of color he sees in the drop-in center often deal with issues around self-affirmation and self-efficacy. He offered a typical example of the kind of thought process a young man might have in choosing his behavior. "If I feel that having sex with another man is sinful and I'm going to hell for it and I'm a bad person for it, then why the hell should I use a condom? Why shouldn't I go all out? You already think I'm a devil anyway."

West recalled one group discussion in particular. "At one point it got really emotional," he said. "A lot of it was linked to how these young men for years and years have to listen to messages about how demonic gay people are, how bad and awful," said West. "I'm not a psychoanalyst," he said, "but 'trauma' comes to mind when you consider that something you see as very much a part of you is demonized. I think it does something to you. It's not just words; it's psychological and verbal abuse. Yet we don't treat Black gay men, gay men of color, or any gay men, as if they've been traumatized and need counseling." This is why, said West, HIV prevention at St. Hope may not "look like" HIV prevention. "No one wants to be reduced," he said. West explained, "Sometimes young men are made to feel that they're just a number," he said. "You can't just see them through the lens of HIV. So they come in and we say 'How are you doing in school? How's the job search?' It goes right back to the notion that if people feel good about their lives, they're more likely to make good decisions."¹⁰⁶⁹

¹⁰⁶⁹. West interview.

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Psychologist Stephen Morin sees research work like Caitlin Ryan's, and holistic approaches to health promotion and HIV prevention such as those Tim'm West described, as examples of a renewed focus on helping gay men recover and build self-esteem in the face of a homophobic society, precisely what the early gay health movement hoped to do. Morin, who returned to San Francisco after serving on the staff of former Speaker of the House Rep. Nancy Pelosi (D-Calif.), today is director of the Center for AIDS Prevention Studies and AIDS Policy Research Center at the University of California–San Francisco. Looking back over his three-decade involvement in addressing the epidemic, he said, "The magnitude of the death and dying and disability has decreased for gay men, and they're starting to go back to issues that were put on the back burner when AIDS hit. All those have to do with self-esteem from early adolescence and childhood, around being 'different.'"

Morin said research is showing the best way to reduce gay men's risk for HIV is to build up our self-esteem and build upon our resilience. Most LGBT people have, after all, survived and thrived in spite of the beatings, bullying, firings, insults, rejections, and second-class citizenship that "different" people face in America. Most of us can only dream of a world—somewhere over the rainbow, perhaps—where families don't reject their gay children, bullies don't drive gay teens to suicide, and all Americans are finally treated with equal justice under law. The possibilities for improved health would be tremendous. Said Morin, "If you take a ten-year-old who grows up in a situation where gay people can marry, they're not discriminated against in the military, and have all these rights, it's less stigmatizing than growing up in a place where people don't have these rights. So ten years later, when you have a gay twenty-year-old and they don't have as many stigmatizing things to deal with, they prob-

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ably don't have the same drug and alcohol behaviors that have been so problematic."¹⁰⁷⁰

Stop AIDS Project director Kyriell Noon told me, "A lot of us who are thinking progressively about the epidemic realize we have to go further 'upstream' to make an impact on prevention. We can hand out condoms forever, and we will as long as people need them. But the greater impact would be to end the things that lead to transmission in the first place—homophobia, social isolation, poverty, homelessness. If we could correct some of that, we'd probably see changes in the numbers around HIV, particularly with communities of color."

For now, we have a lot of wounded men on our hands. But as we have seen throughout the AIDS epidemic, focusing only on what is affordable at the moment undermines what is achievable. Noon said that although there is "intellectual movement" toward a broader and deeper understanding of HIV prevention, "in the end we're constrained by funding streams." He explained, "One of the consequences of early AIDS activism is that we demanded, and got, discreet funding streams for us around [prevention]. Those funding streams are still in existence and they are very limited in the ways they can be used. So if you say to the department of public health, 'I'm getting HIV prevention dollars, but I want to talk about gay men's health, well-being, community, leadership development, eradicate homophobia and racism, and all these great beautiful things,' they say, 'You can't spend the money on that, that's HIV prevention money.'" Noon called this narrow thinking and equally narrow focus of resources "silos."¹⁰⁷¹ So-called "silo-thinking" keeps

¹⁰⁷⁰. Stephen F. Morin, telephone interview with author, 25 June 2010.

¹⁰⁷¹. Noon interview.

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fundings from backing initiatives that are likely to be more lastingly effective simply because they don't "look like" their idea of HIV prevention. There is resistance to the fact that what worked in the eighties may not work in the era of Internet-based social lives, or in more than one community.

After thirty years, it seems realistic prevention for gay and bisexual men of all races—those at greatest risk in the United States of becoming infected with or transmitting HIV—is still held captive by bureaucratic minds and program funding that haven't evolved to meet the men's changed needs. Activists and prevention scientists complain that the so-called "No Promo Homo" amendment sponsored in 1987 by the late Sen. Jesse Helms, prohibiting federal funds from being used to "promote" sexuality, continues to hinder effective targeted prevention messages. Helms successfully argued that supporting efforts to teach gay men to protect themselves against HIV was the same as "promoting" homosexuality.

Judith Auerbach was vice president for public policy with the San Francisco AIDS Foundation at the time our 2010 interview. Formerly with the Office of AIDS Research at the National Institutes of Health, she told me the pernicious effects of the Helms amendment were strongest during the administration of George W. Bush. "Under Bush there was much more active gagging," she said, describing how NIH researchers were put on a "hit list" to be defunded if their scientific studies violated the fragile conscience of the Traditional Values Coalition and its allies in Washington.¹⁰⁷²

Perhaps the two-decade fallout of the amendment has clouded the minds of government funders to the point they can't

¹⁰⁷². Judith Auerbach, interview with author, San Francisco, 19 April 2010.

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understand that effective, targeted HIV prevention will include things like nationwide educational programming and public awareness campaigns aimed at supporting parents to raise healthy, self-affirming LGBT people. These include the Human Rights Campaign Foundation's "Welcoming Schools" initiative,¹⁰⁷³ and anti-bullying efforts like the Trevor Project and the "It Gets Better" and "Give a Damn" campaigns launched in autumn 2010 after a series of gay teens around the country killed themselves because of bullying and harassment. The campaigns feature gay and lesbian celebrities sharing their personal stories of being bullied as youngsters and sometimes even as adults, helping to shine a long overdue spotlight on the harmful behaviors that have emotionally and spiritually burdened so many gay people from our youngest years. In New York, Gay Men's Health Crisis in 2010 relaunched its anti-homophobia "I Love My Boo" campaign. Posters and postcards displayed and distributed throughout the city featured images of young Black and Latino men hugging, kissing, and holding hands, and the tag line, "We're about trust, respect, and commitment." GMHC hoped to promote acceptance and understanding of gay couples by showing the men supporting and loving each other.

Supporting men's personal choices with honest information, frankly stated in language and images they understand, is the core of HIV prevention aimed at gay and bisexual men. How best to provide it continues to elicit a range of views. Some say it's better to scare people again; others support a laissez-faire approach. One thing is certain: Telling gay men to "use a condom every time" started to lose its effectiveness as early as

¹⁰⁷³. Human Rights Campaign Foundation, "Welcoming Schools," at <http://www.welcomingschools.org/>, accessed 2 October 2010.

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1985, when the HIV antibody test first allowed us to know who was and was not infected.

A public education campaign created by the New York City health department in late 2010 showed that, even after thirty years, some public health professionals believed it was reasonable to terrify and shame gay men if it could possibly get them to use condoms. Using frightening and graphic images of anal cancer and dementia, the health department wanted to make sure gay men know that becoming infected with a deadly virus isn't the only thing they need to worry about. "When you get HIV," warned the horror-movie voiceover in the TV and YouTube spots, "it's never just HIV."¹⁰⁷⁴ Unfortunately, though not surprisingly, the New York campaign ignored the drivers of risk behavior—the psychological and spiritual damage from years of bullying, the depression, the loneliness—that might be addressed in a more honest prevention campaign, perhaps with a tagline like this: "It's never just sex." After all, the sexual behavior we choose to engage in is "driven by" all the factors that influence what sex means to each of us within the framework of our unique experience.

Two forums held in San Francisco midway through the past decade offered glimpses into the hearts and minds of gay men trying to navigate the treacherous waters of gay life in America's gayest city. Such forums are where we see Ron Stall's syndemics manifested in real men's life stories, where we hear about why prevention works or fails from the people trying to find their way through the thicket of information and their own psychological "drivers."

¹⁰⁷⁴. Anemona Hartocollis, "City's Graphic Ad on the Dangers of HIV is Dividing Activists," *New York Times* (3 January 2011).

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An all-day, invitation-only meeting in February 2007 brought together a group of a hundred gay men to brainstorm ideas for how to help themselves and others be “healthy homos.” The guest speaker was Kevin Fenton, director of the National Center for HIV, STD and TB Prevention at the CDC. Fenton, an African-American gay man, was in San Francisco as part of a nationwide listening tour. He told the group his goal was to move his center’s focus “away from a message of using condoms every time you have sex to a more holistic approach.” The men discussed major areas of concern: mental health, aging, healthy sexuality, community, and addiction. The men said the old “condom code” had fallen aside and many were choosing their sexual partners or specific sexual activity with a particular partner based on a common HIV status. “Lots of men don’t want to use condoms and are looking for more complex prevention strategies,” said Stop AIDS Project spokesman Jason Riggs at the forum.

Most of those who discussed healthy sexuality called for a change in what they considered a negative prevention model. “We need to find a way to present a holistic sexuality,” said Oakland resident Gabriel Clark, who conducts Body Erotic workshops. “Sex is just not about the physical act. That seems to be where we are stuck.” Some of the men said they felt it was okay to be judgmental about sex, that some sexual behaviors should be condemned. Others complained that HIV and STD testing facilities in the city were putting them down. Although crystal meth was still a problem, the men said cocaine and alcohol had surpassed it among the most abused substances.¹⁰⁷⁵

¹⁰⁷⁵. Matthew S. Bajko, “Forum Seeks ‘Healthy Homo’ Ideas,” *Bay Area Reporter* (8 February 2007).

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In an earlier forum, panelists from the city's health department and others weighed in on other real-life issues that can complicate sexually active gay men's efforts to make healthy choices. About seventy men, mostly in their forties, discussed subjects like porn videos, sero-sorting, and online cruising at a December 2005 meeting sponsored by the San Francisco Gay Men's Community Initiative, a health department project that became a nonprofit in its own right. The men spoke frankly. "Twink barebacking is reprehensible, using kids, paying them to risk their lives," said Titan Media vice president Keith Webb, of the now-prevalent porn movies depicting unprotected anal intercourse. Such films "fetishize internal ejaculation," he said. Several men pointed to Treasure Island Media's 2004 title *Dawson's 20 Load Weekend* as an example of irresponsible gay filmmaking for its celebration of what most rational people would deem suicidal behavior. The company's website boasts of a worldwide demand for the movie, tantalizing buyers to pony up forty-nine dollars with promises of forbidden scenes of a "fresh young man" who "goes from being a barebacking newcomer to a true Power Cumdump as he takes on man after man after man."¹⁰⁷⁶

Treasure Island cameraman Nick Stevens defended the movie in the forum. "Our movies are for models to have sex the way they want," he said. "Why should we not film that?" Clearly he and his fellow filmmakers at Treasure Island Media didn't share the same understanding of gay pride that led the late Falcon Studios founder and president Chuck Holmes, and other proudly gay pornographers, to require condom use in all Falcon videos. Holmes was very clear, when I interviewed him in 1995, that gay filmmakers had a responsibility to help educate gay

¹⁰⁷⁶. Treasure Island Media, at http://www.treasureislandmedia.com/TreasureIslandMedia_2007/cart/DAWSON-S-20-LOAD-WEEKEND.html, accessed 30 September 2010.

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men about safer sex. Times had obviously changed even if the exploitation of gay men by gay men for pleasure and profit was as common, and rationalized, as ever. Apparently Treasure Island Media saw nothing wrong with depicting, in the most graphic terms, what could well be the actual HIV infection of a man whose alleged craving for “cum” was apparently stronger than his lust for life. Maybe that explained the dark, foreboding music used in the *Dawson* trailer.

In early 2010, the Los Angeles-based AIDS Healthcare Foundation (AHF) filed complaints with the California Labor Commissioner against nine agencies that recruit actors for the porn industry. They argued that companies that portrayed and promoted the “forbidden fruit” of unprotected intercourse were endangering the lives of men and women. The agencies’ own websites were cited as proof. Mike Andrew reported in *Seattle Gay News* that the L.A. public health department estimated that condoms and other protection are used in fewer than 20 percent of hardcore heterosexual pornography. The department also pointed out that adult film workers are ten times more likely to be infected with an STD than the non-adult film worker public. AHF president Michael Weinstein said, “It is reckless for these agents to jeopardize the health of their clients by encouraging and profiting from the unsafe, potentially life-threatening behavior of the models and performers they [the agencies] represent.”¹⁰⁷⁷

Men in the forum also talked about how online cruising and “body fetishism”—disembodied body parts displayed in online profiles—were taking a toll on self-esteem and social lives. Websites like Manhunt.net had replaced bars and bathhouses as places to meet and interact in person. Sister Constance

¹⁰⁷⁷. Mike Andrew, “Labor Complaint Targets Porn Industry,” *Seattle Gay News* (23 April 2010), 8.

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Craving, one of San Francisco's famous Sisters of Perpetual Indulgence, said a compulsive, media-focused, Internet-based social and sex life was contributing to a growing sense of isolation. Pointing to the low turnout at marches and memorials, Sister Craving said, "The activism we engage in is seeking dick."¹⁰⁷⁸

How to help gay men enjoy dick safely continues to perplex even the best minds in behavioral research. But while grassroots prevention efforts still tend to push the "use a condom every time" message, academic researchers are testing new ways to support gay men in staying HIV-negative that are informed by a nuanced understanding of what makes us all tick, positive and negative.

"We've still got people in the country trying to promote 'safer sex,'" said University of Minnesota psychologist and sexual health researcher B.R. Simon Rosser. "That doesn't make sense for the way that we've been able to evolve in the twenty-first century." Referring to Michael Callen and Richard Berkowitz's groundbreaking 1983 booklet *How to Have Sex in an Epidemic*, Rosser said, "Somehow that went from a specific moment to being universal guidelines for everybody." The days are past, said Rosser, of putting up a poster, or doing a mass campaign, with the same message for everyone. Rosser said another popular way of doing prevention is also ready for the boneyard of outdated approaches. "We've got to get beyond the physical workshop interventions," he said. He cited a survey of three thousand men that found fewer than half (47 percent) had ever attended a prevention workshop. "If we think we're going to workshop our way out of this epidemic, we're crazy," he said.

¹⁰⁷⁸. Kevin Davis, "Barebacking, Porn Debated at Gay Men's Forum," *Bay Area Reporter* (8 December 2005).

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Rosser said two major shifts have changed the way HIV prevention must be thought about. “The advent of HAART has changed our understanding of the disease,” he said. Despite the sometimes-miraculous benefits of treatment for those with the virus, an unintended consequence for the uninfected is the blasé attitude about becoming infected with a deadly virus known, even with treatment, to cause harm short of death. “We seem to have adopted this notion that anything goes,” said Rosser, “and that if someone gets infected, well, that’s the way it goes.” It troubles him that, as he put it, “There is an idea that says you can either have a great sex life, or stay negative.”

The other big change has been the tremendous increase in the number of men seeking sex online, an estimated two and a half million in the U.S. alone, according to Rosser. This move of gay men away from brick-and-mortar bars, bathhouses, and clubs, has had a huge impact in gay communities around the world. Rosser referred to a study he reported in the journal *AIDS Care*, which reflected the observations of “key informants” from seventeen cities in fourteen countries, including Amsterdam, Auckland (New Zealand), Copenhagen, Johannesburg, London, Miami, Minneapolis, New York, Paris, Prague, Sydney, and Toronto. In all the cities, the virtual gay community was considered to be larger than the offline community. All the cities except those in Eastern Europe reported increased commercialization and less social activism around gay-oriented events. An informant from Miami said, “Organizations around political issues have disappeared. Gay Pride has changed. We’re seeing a huge increase in corporate sponsors like everybody’s in there; they want a piece of it.”

In almost all the cities, the number and popularity of gay bars and clubs were described as declining. An informant reported that in London, the largest online cruising site opened an

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enormous bar in the middle of town with a computer “so you can cruise their site while you’re out drinking.” Another informant, from Copenhagen, said that in his city even “bathhouses now have Internet hook-ups.” Informants attributed changes to gay individuals, couples, and families becoming integrated into mainstream society, and to the diminution of legal and social discrimination. They reported a “collapse” in HIV prevention for men who have sex with men across the cities. For all these reasons, the key informants agreed that blanket recommendations might no longer be generalizable.¹⁰⁷⁹

I asked Rosser what he thought was drawing men to search for sex online. “It’s not that they’re ashamed, it’s anonymous, or more attractive to closeted guys,” he said. “It’s a safer, cheaper, more reliable way of finding someone, and, most importantly, it yields more sex. It has all the advantages of going to a bathhouse without the inconvenience of having to travel halfway across town.” Not only are more men finding partners online, but they are also having more unsafe sex. “What we’ve concluded,” said Rosser, “is that the Internet increases risk primarily by increasing sex.”

Researchers have learned important lessons as they’ve tried to sort out how best to bring sexual health messages to men in the “virtual community” of sex hunters. Foremost, said Rosser, it’s hard for an HIV prevention program to compete in the highly charged sexual environments of the chat rooms and websites where men search for partners. Second, the men who are willing to take a look at an online prevention message want

¹⁰⁷⁹. B.R. Simon Rosser, William West, Richard Weinmeyer, “Are Gay Communities Dying or Just in Transition? Results from an International Consultation Examining Possible Structural Change in Gay Communities,” *AIDS Care* 20(5) (May 2008): 588–595.

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it to be sexually explicit. Rosser explained, “When we did some laboratory studies, where we could watch people’s eyes and see what they were focusing on, getting them to talk out loud about their impressions, they would say, ‘Where’s the naked man?’ They would say ‘I want to see that, or I’m gone.’” Men online want efforts targeting them to be “far more explicit than we’ve ever had to deal with before,” said Rosser. This has been especially difficult to accommodate because HIV prevention programs have become more conservative. Said Rosser, “If you think about it as a graph, imagine a graph with ‘level of explicitness.’ You see a line going up the page, and HIV prevention has been getting less and less explicit. That gap is getting wider and wider, and we’re wondering why gay men aren’t getting the message.” He added, “It’s not that gay men are sexually obsessed. You put any written message online and nobody’s going to read it; it’s a visual communication.”

Rosser said there have been four generations of online HIV prevention interventions. In the first, when the Internet came into use in the mid-nineties, “people took what they did offline and put it online” in very text-heavy, boring formats. Next came “bells and whistles” programs, where someone could get a question answered. Third, and still most widely used at the time of our 2010 interview, are “hybrids” that incorporate both online and offline features, such as readings and a focus group online, or a listserv discussion. Most recently, Rosser said about five research groups are working on a fourth generation that builds on the strengths of the Internet. Although the research looks promising—a trial study retained 88 percent of the men after a year—he said there isn’t likely to be a working program for several more years.

The ‘4G’ online prevention intervention will likely reflect the kinds of long-term health concerns like those discussed in the San Francisco forums. Rosser said “safe sex” came in at twen-

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ty in a list of twenty-one priorities ranked by gay men in his research. Their top priorities were how to be a better lover; men's physical health (such as testicular cancer and prostate health); building a healthy relationship; keeping a long-term relationship; and understanding themselves. The program is likely to tailor a sexual health and risk reduction program for an individual based on information gathered from him about such things as his needs, desires, and HIV status—a sort of online shopping experience where suggested items are displayed for one's consideration based on past purchases and demographic information collected by a website. Rosser said studies show people will tell their personal business to a computer in a way they won't tell a therapist "or even themselves." This personalized prevention has enormous implications, for individuals and for prevention educators. "If we can design and automate interventions," said Rosser, "we can design and set up orgies that work for you, or help a guy to be healthy and celibate."¹⁰⁸⁰

Isa Fernandez, a psychologist and researcher at Nova Southeastern University in Fort Lauderdale, for years has aimed her work at developing prevention interventions for Latino gay and bisexual men in particular. She said these men are affected by the same syndemics as other gay and bisexual men, with the added layers of ethnic differences that present their own challenges. She told me a study of older Latino men found that one of the biggest drivers of their sexual behavior was they simply wanted to be accepted. Fernandez believes prevention works best when it respects the individual. "The individual has to call back his power," she said. "You can't tell a person what to do; you have to help him get there on his own. We didn't do that in the early days of the epidemic. Not everyone responds to each intervention, so we need to have an ar-

¹⁰⁸⁰. B.R. Simon Rosser, telephone interview with author, 2 June 2010.

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mamentarium or pool of interventions that we can offer to people.”¹⁰⁸¹

Another psychologist and researcher, Thomas J. Coates, and his colleagues Linda Richter and Carlos Caceres, observed in *The Lancet* that only what they call “highly active HIV prevention,” like combination therapy for HIV itself, will be effective in holding back the still-swelling tide of new infections globally. They said advances in biomedical HIV prevention, foremost the ability to suppress HIV itself to a level where it is less infectious, provide substantial opportunities to reinvigorate efforts to motivate behavioral change in individuals and “social units,” and to advance structural approaches that seek to change the contexts that contribute to risk. In combination, the biomedical, behavioral, and structural strategies can be used to address local epidemics. The researchers made it clear that the foundation of any effective prevention effort is people knowing their HIV status.¹⁰⁸²

“It used to be treatment versus prevention, and they were kind of competing priorities,” said UCSF Center for AIDS Prevention Studies director Steve Morin. “Over the last three to five years, treatment as prevention has become one of the things that prevention scientists are talking about. It’s a much more unified approach than in the past.” To achieve that unity, Morin said San Francisco has been on a mission to encourage sexually active gay men to test often. He said men who have multi-

¹⁰⁸¹. Maria Isabel (Isa) Fernandez, telephone interview with author, 4 August 2010.

¹⁰⁸². Thomas J. Coates, Linda Richter, Carlos Caceres, “Behavioral Strategies to Reduce HIV Transmission: How to Make Them Work Better,” *Lancet* 372(9639) (23 August 2008): 669–684.

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ple sexual partners should be tested every three months, others every six months, and once a year for those in ongoing relationships or without any major risk. Regular testing allows the opportunity to pick up early HIV infections and get people into treatment as soon as warranted. Morin said this reduces the overall level of HIV in the gay community, and the overall risk for gay and bisexual men. “As the community viral load goes down,” he said of San Francisco, “the number of new infections has gone down—from about 800 in 2004, to 434 in 2008.” Morin attributed the reduction in part to Healthy San Francisco, a city initiative offering medical care for uninsured residents.¹⁰⁸³ He said it’s also due to a new way of thinking in the city about HIV disease itself. He explained, “San Francisco General is not talking so much about ‘chronic HIV’ as AIDS; they talk about it as ‘acquired inflammatory disease.’”

This new way of conceptualizing HIV disease reflects recent understanding that the damage from even well-managed HIV is apparently due to the immune system being hyper-activated, in a state of constant alert because of the ongoing infection. The shift in thinking has led more and more people to be on anti-retrovirals and more of those who are on ARVs to have suppressed, frequently undetectable, HIV infection. Health outcomes improve, said Morin, by “treating inflammation rather than waiting to treat after the immune system is depleted.” Working with HIV-positive people to reduce their viral load “greatly reduces the likelihood that high-risk negatives will become infected,” said Morin. “In some ways it’s great for social-behavioral-policy scientists because we have a new set of challenges to look at beyond condom promotion. We can now work on behavioral and motivational issues behind treatment access,

¹⁰⁸³. San Francisco Department of Public Health, “Healthy San Francisco,” at <http://www.healthysanfrancisco.org/>, accessed 7 October 2010.

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adherence to ARVs, screening for mental health issues, and not focus our time and energy on interventions with high-risk negatives.”

This combined approach of testing, treatment, and behavioral interventions is generating “considerable enthusiasm among prevention scientists that we can greatly reduce the number of infections in the United States,” said Morin. “In some ways this approach is ideal for the gay community, to the extent that it is a community and is receptive to messages that are delivered through the community.” He added, “It still has problems for people with limited access to or sense of connection to the community.”¹⁰⁸⁴

Stop AIDS Project’s Kyriell Noon told me San Francisco’s new emphasis on testing and treating, as spelled out in a February 2010 city prevention plan, focuses heavily on HIV treatment as prevention. Even prevention programs aimed at HIV-positive men emphasize treatment adherence rather than behavior change. “This is a huge ideological shift,” said Noon.¹⁰⁸⁵

Other prevention experts believe that, important as it is, this “biomedicalization” of HIV prevention alone will not be enough to reduce new HIV infections among gay and bisexual men. Former Stop AIDS Project education director Daniel Wohlfeiler, for example, said it is important to reframe behavioral prevention in terms of individuals’ personal power to make healthy choices, and to make “structural” interventions that reduce risk in the community. He listed examples of structural interventions, such as bathhouses removing the doors of their cubicles, and Manhunt adding a profile option that lets someone check a

¹⁰⁸⁴. Morin interview.

¹⁰⁸⁵. Noon interview.

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box that makes it clear to men checking him out that he isn't interested in "party and play," or "P & P," gay shorthand for doing drugs (usually crystal meth) and having sex.

Wohlfeiler said he's been surprised to find even leading gay public health professionals who persist in focusing on what he called the "half-empty glass" view of gay life in America without grasping the self-fulfilling nature of such pessimism. He recalled a presentation at a national conference by a noted gay STD expert who stressed that any intervention aimed at gay men should consider the homophobia, high rates of violence, opposition to same-sex marriage, and the syndemics that can undermine gay men's ability to make healthy choices.

Another way of framing the argument, said Wohlfeiler, would emphasize that never in the history of gay culture have we been as close to having same-sex marriage, or the level of equality we have today. "The more you think about gay men as victims," he said, "or that we think of ourselves as victims, the more resistance there is against interventions that don't let us have our cake and eat it too, if you will. Anything that even remotely smacks of outside interference in choice is rejected without any careful consideration." But merely by focusing on external factors that can affect an individual's choices, Wohlfeiler said we overlook one of the most important influences: the gay marketplace, the network of backroom bars, bathhouses, and websites that cater to gay male fantasies and needs. "It's incredibly efficient," said Wohlfeiler, "a huge engine that runs at top speed all the time, and it's incredibly important to transmission because it helps mixing take place and encourages people to meet new partners without any real thought about whether this person wants the same things I do."

Whether focusing on behavioral, biomedical, or structural prevention interventions, Wohlfeiler said, "It's been hard for us

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to keep tabs on what level of change we need to bring down the curve of the epidemic. We've been terrible at talking about the diversity of risk. We know from data that most men are safe most of the time, some men are safe some of the time, and there's a very small percentage of men who are very unsafe frequently." Epidemics persist, he said, because of interactions between the core groups, those at greatest risk, and others who take some risk. "All the debates are about 'all gay men are like this' or 'all men are like that.' Well, no, we're very different about risk behavior."¹⁰⁸⁶

Beyond condom use, serosorting has been the most widely practiced means for lowering risk. The informal strategy was developed by HIV-positive gay men who decided not to worry about transmitting HIV to an uninfected partner, so chose to limit their partners to other positive men. A 2007 survey reported that 27 percent of gay men in San Francisco—and 40 percent of men ages eighteen to twenty-nine—practiced serosorting in 2002, compared to 19 percent in 1997. "There seems to be a tendency favoring serosorting over condom use, especially among younger men," said Dennis Osmond, whose Universi-

¹⁰⁸⁶. Daniel Wohlfeiler, interview with author, Berkeley, California, 14 April 2010.

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ty of California–San Francisco research team reported the survey findings in the *American Journal of Public Health*.¹⁰⁸⁷

Men who use the Internet to find sex partners regularly use the homegrown risk-reduction serosorting strategy. But while it seems to help HIV-positive men select positive partners, it apparently hasn't increased condom use between partners of different HIV status. A 2006 survey of 1,574 men who have sex with men found that, for positives, 23.8 percent of Internet partnerships involved unprotected anal intercourse with HIV-negative or unknown-serostatus partners compared with 19.6 percent of partnerships that began at bars or nightclubs. Among negatives, 10.3 percent of partnerships formed online involved unprotected anal intercourse with positive partners, compared with 7.9 percent of those that started in bars or nightclubs.¹⁰⁸⁸

One unexpected outcome of serosorting has been that, although it didn't lead to a rise in HIV incidence, the rate of syphilis increased among gay and bisexual men. "If persons

¹⁰⁸⁷. D. Osmond, L. Pollack, J. Paul, J. Catania, "Changes in Prevalence of HIV Infection and Sexual Risk Behavior in Gay and Bisexual Men in Probability Samples of San Francisco Residents, 1997-2002. *American Journal of Public Health* 97 (2007):1677–1683; Sabin Russell, "Sexual Practices Shifting, SF Studies Find," *San Francisco Chronicle* (27 April 2007), at http://articles.sfgate.com/2007-04-27/bay-area/17241603_1_hiv-status-men-in-san-francisco-gay-men, accessed 3 October 2010.

¹⁰⁸⁸. M. Berry, H.F. Raymond, S. Behel, T. Sanchez, W. McFarland, "Effect of the Internet on Serosorting and Risky Sexual Behavior Among Men Who Have Sex With Men," *International Conference on AIDS* 2006 Aug 13-18;16 Abstract No. Tu-PE0471.

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who are the same HIV serostatus are in the same networks so that positives are having unprotected sex with positives and negatives with negatives, then you could see an increase in syphilis transmission without an increase in HIV transmission,” said Willi McFarland, director of HIV/AIDS statistics and epidemiology for the San Francisco Department of Public Health.¹⁰⁸⁹ McFarland’s boss, department director Mitchell Katz, said, “As an HIV prevention strategy, serosorting is quite effective for positive and negative couples. For positive men, they don’t have to worry about HIV transmission to somebody who is negative. You do still have to worry about [STDs]. But for many HIV-positive men, serosorting brings with it a tremendous psychological relief.” For HIV-negative couples, serosorting is only as reliable as each partner’s knowledge of his current HIV status. “How recently was he tested? People worry about the window period,” said Katz, referring to the time after infection when someone can still test negative because the body hasn’t yet generated sufficient antibodies to be detectable by commonly used screens. “Even if the person is telling you the truth as they know it, how certain can someone be about the truth?”¹⁰⁹⁰

A six-city study from 1999 to 2003 found that men used what the researchers called “seroadaptation” to choose partners and specific sexual activities, including serosorting to select partners of the same HIV status and seropositioning to determine which partner would be “top” and “bottom.” They found

¹⁰⁸⁹. “San Francisco Serosorting May Explain Odd HIV Data: STDs Have Risen, But Not New HIV Infections,” *AIDS Alert* 19(5) (24 May 2004): 55.

¹⁰⁹⁰. Christopher Heredia, “A Serosorting Story,” *San Francisco Chronicle* (12 February 2006), at http://articles.sfgate.com/2006-02-12/living/17280096_1_hiv-status-long-term-hiv-survivors-negative-counterparts, accessed 3 October 2010.

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that positive men were twice as likely to use condoms with negative partners, and negative partners were more likely to be on top in a mixed-status coupling. Serosorting did not increase risk and was even associated with a small protective effect. For this reason the researchers advised that counseling and health messages should continue to emphasize condom use and reducing numbers of partners as the mainstays of individual prevention efforts. Moreover, they affirmed that increasing the benefits of serosorting requires knowing one's HIV status through increased testing frequency, improved test technology, and the continued development of strategies to increase disclosure with partners.¹⁰⁹¹

But even strategies to increase testing and disclosure are likely to have limited effectiveness as long as there is still tremendous stigma about having HIV. Tim'm West in Houston said, "I think a lot of people who haven't been tested know, but haven't been tested because they're afraid of the stigma that comes along with it." At Houston's St. Hope Foundation, West told me, "Part of what we do is to create a place where new social norms can be formed. For example, you have a community here where it's not acceptable, if someone is going for testing, to put them down. We have young men who are fairly open about their HIV status to their peers."

In the Black community, said West, "people don't want to be tested, especially if they're men, because of the association [of HIV] with homosexuality." He added, "It's probably a positive

¹⁰⁹¹. Susan S. Philip, Xuesong Yu, Deborah Donnell, Eric Vittinghoff, Susan Buchbinder, "Serosorting Is Associated with a Decreased Risk of HIV Seroconversion in the EXPLORE Study Cohort," *PLoS One* 5(9) (2010): e12662, published online 9 September 2010, doi: 10.1371/journal.pone.0012662, accessed 3 October 2010.

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thing the CDC has done in destigmatizing identity and focusing on behavior. So in some sense I'm a fan of 'MSM' because it focuses on behavior rather than identity."¹⁰⁹² Or, as Russell Thornhill at the Minority AIDS Project in Los Angeles, put it, "We need to talk about the 'what' [specific sexual activities] rather than the 'who' [identity] in addressing African-American young men."¹⁰⁹³

Even among white gay men in San Francisco, presumably among the best informed about HIV because of the years and layers of awareness in the city, Project Inform's Dana Van Gorder has been dismayed by what he called the "schizophrenia in the community." He explained, "On one hand, people say if I seroconvert I'll take these medications. On the other hand, I've had friends who seroconverted, and you can tell by their reaction they know this is no small matter. Everyone would greatly prefer not to have HIV. "People know this is not something you want to have on a medical level, on a social level, on a sexual level," Van Gorder continued. "And not being in a long-term relationship, all you have to do as an HIV-positive guy is spend two minutes on the hookup sites and you experience, on a very profound personal level, how much rejection within our own community there is focused on HIV-positive men." He said that, although he encourages and supports HIV-negative men to remain uninfected, "There is some pretty palpable hostility that I don't think is necessary."¹⁰⁹⁴

Fred Swanson, director of Seattle's Gay City Health Project, told me HIV testing "is underutilized in our communities as a

¹⁰⁹². West interview.

¹⁰⁹³. Thornhill interview.

¹⁰⁹⁴. Van Gorder interview.

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connection opportunity and a way to get guys involved or even just thinking about why their community matters.” As he sees it, “Testing is a way of bringing gay men into the community,” he told me, “to feel like their community cares about them.” Of course a man can go to a public health clinic for testing. But Swanson said a testing site like the one at Gay City’s East Pike Street location offers men a sense of being cared for by other gay men. “Sure, there’s home access, where people can do testing at home,” said Swanson. “But for the most part people need to leave their homes to get tested. So that’s a great opportunity to talk with guys who come in—about ‘Where are you meeting people? What does that mean to you? How are you making connections?’—and give them opportunities to explore other alternatives in terms of having other things to get involved with.”

Because of its location in tech-savvy Seattle, Swanson said Gay City is using social media such as Facebook and Twitter, and its presence on gay-focused sites like Manhunt and Adam4Adam, to reach out to gay men. Another Gay City project, called Gay City TV, uses a series of interviews with men, posted in a variety of places online where Swanson said they can “get the guys while they’re on the computer and waiting for someone to respond, or just tooling around on the Internet.” Gay City worked with Seattle filmmakers to edit the individual interviews into longer thematic documentaries focused on such subjects as aging and community. The films were promoted around the city, and people would come for a viewing. “I think it was successful,” said Swanson. “We got some really great films out of it and had some rich discussions.” Swanson recognized that it wasn’t like the Gay City forums of the late nineties, with three hundred to four hundred people; it was more like seventy-five. But he said it was an interesting attempt

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to use the technology that people are accessing and try to use it to get people engaged and involved.”¹⁰⁹⁵

In its first fifteen years—they were celebrating what they called their “Quinceañera” when I visited them in 2010—Gay City Health Project had become part of the fabric of the community. On the ground floor of their building they lease space to a pleasant coffeehouse, Kaladi Brothers Coffee. Having the coffeehouse was an intentional way of being a good neighbor and contributing to the community on a different level, Swanson told me. Expanding their focus beginning in 2000 from solely HIV/AIDS to other aspects of gay men’s health was another way Gay City has remained relevant in the community. Now it offers programs like “Party Smart,” a campaign designed to address substance abuse in a nonjudgmental way; “Domestic Disturbance,” a forum about male-on-male domestic violence; and “Out to Quit,” a smoking cessation program that has had very good success.¹⁰⁹⁶ “The work of Gay City is as critical as ever,” said deputy director Peter Jabin, who runs the group’s monthly “Queerituality” meetings focused on spirituality. “We are carrying a vision of the gay community as gifted, special, strong, and *called*.”¹⁰⁹⁷

Gay City’s investment in the health of Seattle’s gay residents has yielded benefits for the city and beyond, as the agency’s programs have been replicated in other places. Getting to this point has taken a great deal of time, creativity, and

¹⁰⁹⁵. Fred Swanson, interview with author, Seattle, 21 April 2010.

¹⁰⁹⁶. James Whitely, “Gay City Quinceañera Celebrates 15 Years of Community,” *Seattle Gay News* (23 April 2010), 4.

¹⁰⁹⁷. Peter Jabin, interview with author, Seattle, 21 April 2010.

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relationship building. As essential as this slow-brewing process is for programs to work in effecting real change, it is the exception rather than the norm. It seems more common for projects to be funded by the CDC, and then, sometimes just as they are becoming established in the local community, the funding gets cut because of what seems like political pressure to shift focus to another demographic. The result can be disillusioning, possibly damaging, as people who believed the project actually cared about them and was investing in their long-term health watch it simply go away.

Gregory M. Rebchook is an assistant professor and researcher at the University of California–San Francisco’s Center for AIDS Prevention Studies. He told me that in the late eighties and early nineties there was concern that all the HIV prevention interventions in use and development for gay men were reaching older men. So a lot of projects were created to target the men these programs were missing, mainly younger gay and bisexual men. “Now the pendulum has swung the other way,” said Rebchook. Although we still need more evidence-based interventions for gay and bisexual men in general, he said they mostly focus on young men and men of color. The prevention needs of older men have “fallen off the radar screen in some respects.”

I was incredulous that interventions hadn’t already been developed to target men in their thirties and older when the CDC reports that, among white gay and bisexual men, those most at risk are in their thirties—followed by men in their forties. Among Hispanics/Latinos, 35 percent of new HIV infections are in men between thirty and thirty-nine years of age.¹⁰⁹⁸ “We haven’t

¹⁰⁹⁸. CDC, “Subpopulation Estimates from the HIV Incidence Surveillance System—United States, 2006,” *MMWR* 57(36) (2008):985–989.

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thought about what needs middle adulthood guys bring to the table,” said Rebhook. He suggested there may be a way to build an intervention around Danish-German-American developmental psychologist Erik Erikson’s theory that people in midlife are motivated by what Erikson called “generativity,” the need to give of oneself to the younger generation and community.¹⁰⁹⁹ “The old approach might have been more ‘one size fits all,’” said Rebhook, “but we’re realizing that hasn’t worked as well as we thought it would. It doesn’t address the particular needs a lot of groups have.”

Rebhook was a member of the team that developed the widely replicated MPowerment project, a cornerstone of Gay City’s own community-focused approach to health. MPowerment¹¹⁰⁰ uses outreach, drop-in centers and other ways to build community among men between ages eighteen and twenty-nine. The intervention is one of the CDC’s widely replicated DEBI (Dissemination of Behavioral Interventions) model programs.¹¹⁰¹ Shortly before our interview, Rebhook had assessed for CDC ten sites that were using the MPowerment model. One was a new project, in Dallas, that was adapting

¹⁰⁹⁹. Wikipedia, Erik Erikson, at http://en.wikipedia.org/wiki/Erik_Erikson, accessed 4 October 2010.

¹¹⁰⁰. S.M. Kegeles, R.B. Hays, T.J. Coates. “The Mpowerment Project: A Community-level HIV Prevention Intervention for Young Gay Men,” *American Journal of Public Health* 86 (8) (1996):1129–1136.

¹¹⁰¹. CDC, Dissemination of Behavioral Interventions: The Mpowerment Project: A Community-Level HIV Prevention Intervention for Young Gay Men at http://www.cdc.gov/hiv/topics/prev_prog/rep/packages/mpower.htm, accessed 4 October 2010.

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MPOWERment for young African-American men. He told me how the model had to be adjusted to reach both men who socialized mainly with white gay men and those who socialized among African-Americans. A recent program had attracted 150 men. "When you put resources into it, you can engage the community," said Rebchook.

But there's the rub for HIV prevention in the US, as Kyriell Noon spelled it out: resources, funding streams. "MPOWERment takes time and investment," said Rebchook. "It's not something you can do in six months or one year. You have to make an investment in the community." He described what happens when that long-term investment isn't made. What he called a "strong program," in Orange County with which he'd worked for five years wasn't refunded in the latest round of CDC awards. "So they have to cancel the project. Just as they've developed the reputation in the community, and have a vibrant program with young gay men, the funding goes away." He added, "I feel like our whole system doesn't make the investment in communities."¹¹⁰²

The Obama administration's 2010 National HIV/AIDS Strategy, the country's first attempt in thirty years to create a coordinated plan to address the domestic epidemic, makes it clear the government expects the LGBT community to step back to the plate in doing our own HIV prevention education work. "The burden of addressing the HIV epidemic among gay and bisexual men and transgender individuals does not rest with the government alone," says the strategy document. "Early in the epidemic, the lesbian, gay, bisexual and transgender (LGBT) community developed its own education campaigns and institutions to reduce HIV infection in the wake of inaction by govern-

¹¹⁰². Gregory M. Rebchook, telephone interview with author, 14 July 2010.

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ment and other institutions. Continuing these efforts is important to our success.”¹¹⁰³

Which sounds okay until you recall that, in those early years of government inaction, gay Americans were forced to create and pay for our own prevention brochures, public education, services, and even medical research precisely because neither the government nor most private sources of funds early on considered the lives of gay men valuable enough to protect. The 1987 Helms amendment (“No Promo Homo”) prevented taxpayer dollars from funding the targeted, explicit prevention efforts aimed at men who have sex with men that public health experts have recommended since the beginning of the epidemic.¹¹⁰⁴ This meant the gay community had to carry the burden of funding prevention efforts aimed at the largest single group of Americans at risk—while the government paid for generic information aimed at no one in particular. Will the government now be willing, finally, to provide proportionate support for prevention initiatives created by and for gay and bisexual men? We have already waited three decades too long.

Of course the risk of relying on government support is that it can be rescinded as readily as it is given. A progressive administration is a natural ally of those most affected by HIV, as Democrats typically appeal to people of color and gay people. But

¹¹⁰³. White House (ONAP), *National HIV/AIDS Strategy for the United States*, 14.

¹¹⁰⁴. Coolfont Report: A PHS Plan for Prevention and Control of AIDS and the AIDS Virus,” *Public Health Reports* 101 (July–August 1986): 341-48; Institute of Medicine/National Academy of Sciences, *Confronting AIDS: Directions for Public Health, Health Care, and Research* (Washington, DC: National Academy Press, 1986), see especially 95-105.

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it's wise to remember that America has had Democratic presidents for only eleven of the first thirty years of AIDS. As we've learned throughout these decades, progress on HIV prevention—by either the government or gay men—cannot be taken for granted. Never in the AIDS years has the government tightened its embrace to more strangulating effect on HIV prevention than when the CDC, under George W. Bush, felt the need to harass San Francisco's Stop AIDS Project. Beginning its first year, the Bush administration worked systematically to dismantle the progress that had been made under President Bill Clinton to help Americans make informed choices about our intimate behavior. Under Bush, the CDC pulled information from its website about the effectiveness of condoms in preventing HIV transmission. Nancy Reagan's 1986 message of "just say no" to drugs was now expanded to sex, as right-wing political appointees squandered taxpayer dollars on scientifically disproved abstinence-only programs aimed at the nation's young people.

At the same time, Bush's Department of Health and Human Services was busy "investigating" and trying to impose inverted right-wing "logic" on HIV prevention programs by threatening to defund programs aimed at teaching safer sex if their content was considered too sexually explicit.¹¹⁰⁵ After questioning Stop AIDS staff over two days, CDC investigators concluded that "the design and delivery of the agency's prevention activities was based on current accepted behavioral science theories in

¹¹⁰⁵. Maggie Mason, "Review Ordered for HIV Programs to See If Campaigns Too Sexy," Associated Press (16 November 2001).

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the area of health promotion.”¹¹⁰⁶ Nevertheless the Bush administration ordered the project in June 2003 to immediately halt several of its programs that “appear to encourage or promote sexual activity”—or risk losing about half a million dollars in CDC funding. Stop AIDS demurred, and the government slashed its funding in 2005, as threatened. For good measure, and directly contradicting the Republican party’s professed belief in states’ rights and local control, the CDC under Bush also said its own review process should be changed to prevent local review committees from condoning “obscene” materials like those the Stop AIDS Project used to communicate with gay men about HIV prevention.¹¹⁰⁷ Fortunately, the city of San Francisco made up for the lost funding, according to Stop AIDS director Kyriell Noon.¹¹⁰⁸

While the conservative administration was harassing prevention programs serving gay men here in the United States, it was also forcing its puritanical moral agenda onto developing countries by restricting two-thirds of the prevention funding in Bush’s then-new PEPFAR global AIDS program to scientifically unsound “abstinence/be faithful” messages. In 2006, the Gov-

¹¹⁰⁶. Ray Delgado, “AIDS Workshops Pass Federal Test: Tone of S.F. Group’s Safer Sex Sessions Survives Legislator’s Challenge,” *San Francisco Chronicle* (20 February 2003).

¹¹⁰⁷. Ceci Connolly, “U.S. Warns AIDS Group on Funding,” *Washington Post* (16 June 2003).

¹¹⁰⁸. Noon interview.

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ernment Accountability Office (GAO) strongly criticized the program's ideological focus.¹¹⁰⁹

Under President Obama, this much at least seemed certain: There was recognition, at the highest levels of the government, up to and including the president himself, that HIV/AIDS in America remains, as it has been for thirty years, a health crisis largely among gay and bisexual men of all skin tones and ethnicities. In fact, the National HIV/AIDS Strategy calls for a reprioritization of resources and attention to finally address what the document calls "the starkness and the enduring nature of the disparate impact on gay and bisexual men."¹¹¹⁰ It further states, accurately if not apologetically, "Our national commitment to this population has not always reached a level of HIV prevention funding reflective of their risk."¹¹¹¹

According to its website, 43 percent of CDC's Division of HIV/AIDS Prevention's fiscal year 2009 budget was targeted towards men who have sex with men, and MSM who are also injection drug users (IDU). Together, the two groups account for

¹¹⁰⁹. Government Accountability Office. *Spending Requirement Presents Challenges for Allocating Prevention Funding under the President's Emergency Plan for AIDS Relief*. (Washington, DC: US Government Accountability Office, April 2006.)

¹¹¹⁰. National AIDS Strategy, 14.

¹¹¹¹. NASTAD and Kaiser Family Foundation. The National HIV Prevention Inventory: The State of HIV Prevention Across the US (July 2009). At <http://www.kff.org/hivaids/upload/7932.pdf>, accessed 7 October 2010.

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most AIDS cases and new HIV infections in the U.S.¹¹¹² On 27 September 2010, the centers launched a new website featuring information about and for gay and bisexual men (cdc.gov/msmhealth) in conjunction with the third annual National Gay Men's HIV/AIDS Awareness Day, which it also sponsored. Division director Kevin Fenton issued a statement saying, "Although it has been nearly thirty years since the first reported cases of HIV among gay and bisexual men, HIV remains a crisis that is far from over in this community."

Fenton noted figures indicating that one in five gay and bisexual men in twenty-one American cities is HIV-positive and nearly half are unaware of their infection.¹¹¹³ "While the numbers are stark," he said, "we cannot allow gay and bisexual men to believe that HIV infection is inevitable." He recommended yearly testing for all HIV-negative men, whether they think they are at risk or not, and more frequent testing for those with anonymous partners and at higher risk. "Finding out you have HIV is hard," he said, "but not knowing is even worse and puts your life and others' lives at risk." Fenton also said the Obama administration would continue to show leadership in addressing HIV among gay and bisexual men—in particular by making HIV prevention for MSM a central part of the nation's HIV/AIDS strategy, and in a new CDC initiative to integrate HIV preven-

¹¹¹². CDC, HIV among Gay, Bisexual and Other Men Who Have Sex with Men (MSM) (September 2010), at <http://www.cdc.gov/hiv/topics/msm/index.htm>, accessed 7 October 2010.

¹¹¹³. CDC, *Morbidity and Mortality Weekly Report* 59 (Sept. 24, 2010):1201–1207.

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tion into a holistic approach to gay and bisexual men's health the president would propose in his fiscal 2011 budget.¹¹¹⁴

Fenton didn't mention that only a minuscule 3 percent of President Obama's requested fiscal 2011 budget of \$27.2 billion for domestic and global AIDS was devoted to domestic US HIV prevention.¹¹¹⁵ If appropriately reprioritized, as the National HIV/AIDS Strategy promised funding would be, a proportionate share of that \$947.7 million could do a tremendous amount of good in terms of preventing new HIV infection among men who have sex with men. How much good, exactly, would depend largely on whether or not the albatross known as the Helms amendment could at last be laid to rest with its antediluvian namesake so that targeted, explicit messages can reach their intended audience in a way they understand.

Activists I interviewed agreed overturning the insidious amendment and funding realistic prevention would be an ideal continuation of the long-overdue changes President Obama brought to the country's response to HIV/AIDS in his first two years. Overturning the ban on federal needle exchange programs, lifting the ban on HIV-positive visitors coming to the US, and releasing the first-ever national HIV/AIDS strategy are big steps forward, of course. But the impact of a prevention strategy unencumbered by an absurd prohibition of frank discussion

¹¹¹⁴. CDC, "Re-energizing the Fight," Statement by Kevin Fenton, MD, Ph.D., National Gay Men's HIV/AIDS Awareness Day: September 27, 2010, at <http://www.cdc.gov/nchhstp/newsroom/NGMHAAD2010Statement.html>, accessed 7 October 2010.

¹¹¹⁵. Kaiser Family Foundation, *HIV/AIDS Policy Fact Sheet: US Federal Funding for HIV/AIDS: The President's FY 2011 Budget Request*, (February 2010), at <http://www.kff.org/hivaids/upload/7029-06.pdf>, accessed 2 October 2010.

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of sex and sexuality, in materials aimed at changing sexual behavior rather than sitting on a shelf, could have the most dramatic effect of all. “We need to overturn the Helms amendment,” said NAPWA president Frank Oldham. “It’s like having Jim Crow laws on the books and saying we have them on the books but we haven’t overturned them because we don’t practice them. It needs to be overturned and HIV prevention needs to be culturally appropriate.”¹¹¹⁶

¹¹¹⁶. Frank Oldham, telephone interview with author, 4 May 2010.

FORTY-TWO

For better and for worse, the drama around HIV/AIDS has waned considerably over the years since effective treatment was introduced in 1996. The angry ACT UP demonstrations of the late eighties faded into memory as soon as treatment brought HIV infection as close as it has ever been to being a chronic, manageable condition often likened to diabetes.

In 2010, I asked Robert M. Wachter, professor and associate chairman of the department of medicine at the University of California–San Francisco, to reflect on the comments he’d made in his 1992 *New England Journal of Medicine* article crediting AIDS activists with showing how to be effective patient advocates.¹¹¹⁷ “Clearly the advent of HAART markedly dialed down the urgency of the advocacy movement,” said Wachter. “In the early days, individuals within the gay community, and the community itself, had a palpable sense of impending doom, and a feeling that the establishment needed to be kick-started to pay attention to their needs.” Although the sense of impending doom has waned, Wachter said, “The community is also now quite dependent on the establishment (and has been co-opted into it, to an extent) to produce these life-saving drugs.” He likened the loss of urgency about AIDS to the difference between anti-war protests of the 1960s, “when the threat of the draft was real,” and the lack of anti-war efforts today. “Activism

¹¹¹⁷. Robert M. Wachter, MD, “AIDS, Activism, and the Politics of Health,” *New England Journal of Medicine* 326 (9 January 1992): 128–32.

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is hard,” he said, “and requires the fuel of a real and present danger, which—thankfully—has waned in HIV/AIDS.”¹¹¹⁸

Many of those with access to treatment lost their activist zeal once they weren’t so worried about whether they would live or die. Activism has also faded because so many early warriors have died, from AIDS and other causes. A very incomplete list of notable leaders who have died in just the last few years includes Rodger McFarlane,¹¹¹⁹ whose personal phone-turned-information-hotline became the world’s first AIDS service, and who was the first paid director of Gay Men’s Health Crisis, the world’s first AIDS service organization; Eric Rofes,¹¹²⁰ prolific author, organizer, and former executive director of the Los Angeles Gay and Lesbian Center and of San Francisco’s Shanti Project; Alice Foley,¹¹²¹ the indomitable town nurse in Provincetown, Mass., whose curiosity and compassion led her to check in on homebound men dying of AIDS in the earliest years, and then to start the Provincetown AIDS Support Group; and Martin

¹¹¹⁸. Robert M. Wachter, M.D., e-mail to author, 16 June 2010.

¹¹¹⁹. Dennis Hevesi, “Rodger McFarlane, Who Led AIDS-Related Groups, Dies at 54,” *New York Times* (18 May 2009), at <http://www.nytimes.com/2009/05/19/nyregion/19mcfarlane.html>, accessed 14 October 2010.

¹¹²⁰. Bryan Marquand, “Eric Rofes, 51, Longtime Gay Rights Activist,” *Boston Globe* (2 July 2006), at http://www.boston.com/news/globe/obituaries/articles/2006/07/02/eric_rofes_51_longtime_gay_rights_activist/?page=2, accessed 13 October 2010.

¹¹²¹. Emma Stickgold, “Alice Foley, Early AIDS Activist as Provincetown Nurse; at 76,” *Boston Globe* (2 May 2009), at http://www.boston.com/bostonglobe/obituaries/articles/2009/05/02/alice_foley_early_aids_activist_as_provincetown_nurse_at_76/, accessed 13 October 2010.

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Delaney,¹¹²² founder of Project Inform, advisor on HIV drug research, now the namesake of the National Institute of Allergy and Infectious Disease's new research initiative aimed at finding a cure for HIV.

Still other activists, such as Paul Boneberg, director in the eighties of the San Francisco group Mobilization Against AIDS, wanted to move onto something else in their lives after years of channeling their energy into HIV. "I wanted to have my life expand beyond HIV/AIDS," Boneberg told me in his office at the San Francisco GLBT Historical Society. "I felt like I was the millionth voice, so it wasn't activism anymore."¹¹²³

When I last interviewed him, in 1995, Moisés Agosto was hoping his health would hold until more effective HIV treatment was found. The following year, combination therapy came into use and things began to turn around dramatically for Agosto, like so many others. The former National Minority AIDS Council treatment advocate and ACT UP/New York member returned home to Puerto Rico. About to turn forty-five when I spoke with him in 2010, Agosto told me, "It's not a burden anymore. It's not in my face so that I'm scared every day. I've been undetectable for ten years, and have had eight hundred to nine hundred T-cells for a long time. Suddenly it's a matter of taking my pills, going to the doctor, getting my labs."

I ask how this dramatic shift has affected the rest of his life. "There was a time in my life when my identity was defined by

¹¹²². Dennis Hevesi, "Martin Delaney, 63, AIDS Activist Dies," *New York Times* (26 January 2009), at <http://www.nytimes.com/2009/01/27/us/27delaney.html>, accessed 13 October 2010.

¹¹²³. Paul Boneberg, interview with author, San Francisco, 15 April 2010.

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my disease,” he told me. Today, he said, “I don’t go to people and say ‘I’m Moisés, and I’m HIV-positive.’” He explained, “It’s an exercise in letting go, to rescue the life you want.” Returning to Puerto Rico, he said, “I had a need to go back to me, to my origin, to find Moisés—not Moisés, last name AIDS.”¹¹²⁴

Regardless of why some individuals left or modified their involvement in AIDS advocacy, *POZ* magazine founder Sean Strub told me in 2010, “We as AIDS advocates in the gay community need to really celebrate and respect what we accomplished, not just historically but now.” The awareness and empathy gay advocates gained from their involvement can’t be easily replaced. Said Strub, “We remember feeling so abandoned by the broader society in the eighties, so left to die. That’s a feeling that a lot of communities, poverty communities in particular, have felt for a long time.”

It is hard not to conclude that too many white middle-class gay men have done what the self-serving do: Take their prize and turn their backs on their brethren, leaving them to fend for themselves. “Once the identity of the epidemic moved from gay white male communities to communities of color,” said Strub, “we were just as willing to abandon them as everybody else was to abandon us.”¹¹²⁵

Yet it was the willingness of gay American AIDS advocates to stand in solidarity with people living with HIV in other countries that led to tremendous change in addressing the global pandemic and advancing the human rights of same-sex-loving

¹¹²⁴. Moisés Agosto Rosario, Skype interview with author, 13 July 2010.

¹¹²⁵. Sean Strub, interview with author, New York City, 27 July 2010.

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people. Paul Boneberg, who was one of the first American activists to get involved with HIV/AIDS on the global level, said the US activist response was unique because of its foundational document, the Denver Principles. The 1983 manifesto insisted people with HIV/AIDS be given, and take, an active role in their own treatment and care as well as in shaping services intended for them.¹¹²⁶ He pointed out that the principles were adopted by the United Nations in its 1994 Greater Involvement of People Living with HIV/AIDS (GIPA)¹¹²⁷ policy, and other countries require the involvement of people with AIDS as a condition of program funding.

Gay American AIDS activists, particularly members of ACT UP/New York, helped equip their counterparts in other countries with the support and training they needed to stimulate responses to the epidemic in many AIDS-ravaged countries of the developing world. Former ACT UP/New York member Gregg Gonsalves told me contacts with such activists as Zachie Achmat, the founder of South Africa's Treatment Action Campaign, helped spread information and build organizing skill. "There were already connections established," said Gonsalves. "Because of the Internet and ease of communication, the ties exploded all over the world. In 2003, we organized a meeting in South Africa with people from sixty-seven countries on how to organize globally."¹¹²⁸ Mark Harrington, another former ACT UP/New York member and executive director of the New York-

¹¹²⁶. Boneberg interview.

¹¹²⁷. United Nations Programme on HIV/AIDS (UNAIDS), "Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)," at <http://www.unaids.org/en/PolicyAndPractice/GIPA/default.asp>, accessed 11 October 2010.

¹¹²⁸. Gonsalves interview.

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based Treatment Action Group (TAG), told me, “The PWA [people with AIDS] movement has made space in some of the most repressive societies.”¹¹²⁹

As it did in the United States, said Gonsalves, “AIDS has driven gay and lesbian organizing.” But he added, there has been a “huge backlash”—exactly what American gay and lesbian activists feared would happen in the U.S. in the early years of AIDS. He pointed to the arrest and imprisonment in Malawi of a gay couple after the men held a private party to celebrate their engagement. Malawi, like many former British colonies, has held onto its colonial anti-sodomy laws years after Britain itself abolished its own.

It’s painful to read the *New York Times* account of the men’s sentencing to the maximum fourteen years of hard labor in prison for what the government called “unnatural acts” and “gross indecency”—the same charge that landed Oscar Wilde in prison in 1895, though he was sentenced in London to “only” two years of hard labor. Barry Bearak reported, “The couple—Tiwonge Chimbalanga, thirty-three, and Steven Monjeza, twenty-six—remained still as they heard the sentence, though Mr. Monjeza was seen weeping after the two were handcuffed and led away. As with earlier court appearances, a sizable crowd was outside, mostly to ridicule the men and rejoice at the spectacle.”¹¹³⁰

¹¹²⁹. Mark Harrington, interview with author, New York City, 28 July 2010.

¹¹³⁰. Barry Bearak, “Gay Couple in Malawi Get Maximum Sentence of 14 Years in Prison,” *New York Times* (20 May 2010), at <http://www.nytimes.com/2010/05/21/world/africa/21malawi.html>, accessed 12 October 2010.

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Fortunately, the two young men were released and pardoned by Malawi's president after being pressured by human rights and donor organizations assisting the impoverished nation. Even Sir Elton John leaned on the president in an open letter in London's *The Guardian* newspaper. Reminding President Bingu wa Mutharika that 12 percent of Malawi's population has HIV and seventy thousand of his countrymen die from AIDS each year, John wrote, "Discrimination...costs lives. Explicitly excluding or stigmatizing a particular subgroup serves only to drive that population into the shadows, thus perpetuating and complicating—rather than ameliorating—the AIDS epidemic."¹¹³¹ United Nations Secretary General Ban Ki-moon praised Mutharika's decision as "courageous," even as he pointed out, "This outdated penal code should be reformed wherever it may exist."¹¹³²

As he sees it from London, journalist and author Neil McKenna said little has changed in the developing world for gay and bisexual men since he surveyed the global landscape in his groundbreaking 1996 report *On the Margins: Men Who Have Sex with Men and HIV in the Developing World*¹¹³³ He told me in 2010, "Virtually no research has been conducted.

¹¹³¹. Elton John, "My Friend, President Mutharika, Show Compassion," *The Guardian* (29 May 2010), at <http://www.guardian.co.uk/commentisfree/2010/may/29/aids-malawi-chimbalanga-monjeza>, accessed 12 October 2010.

¹¹³². "Malawi Pardons Jailed Gay Couple," BBC News (29 May 2010), at <http://www.bbc.co.uk/news/10190653>, accessed 12 October 2010.

¹¹³³. Neil McKenna, *On the Margins: Men Who Have Sex with Men and HIV in the Developing World* (London: Panos Institute, 1996).

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There is an absence of urgency, of funding, of responsibility when it comes to HIV/AIDS.” Although there is a “nascent gay movement” and “consciousness” in a few places, such as South Africa, McKenna said, “If you try to replicate that consciousness almost anywhere else in the world, it simply doesn’t exist.” Covert sexual organizing of middle-class homosexuals in such big cities as Karachi, Mumbai, and Beijing, does not a gay movement make, said McKenna. Yes, they reflect progress. “But,” he said, “they are not the response to what we wanted in the early eighties and nineties, which was for AIDS to become a catalyst for human rights for MSM. That hasn’t happened.”¹¹³⁴

In 2008, the American Foundation for AIDS Research (AmFAR) reported a shocking picture of HIV/AIDS among gay and bisexual men worldwide—and the “out of sight, out of mind” attitude of most governments toward men who have sex with men in their own countries. These countries mostly have not been required as a condition of donors’ generosity to abide by the same human rights codes and laws as the donor nations themselves. Of course this would get awkward for the United States, given the fact that gay Americans have not yet been recognized as full, equal citizens as defined by the nation’s own foundational document, the Constitution, although the Obama administration in 2009 did finally endorse the United Nations declaration calling for the worldwide decriminalization of homosexuality that George W. Bush had refused to sign.¹¹³⁵

¹¹³⁴. Neil McKenna, Skype interview with author, 2 August 2010.

¹¹³⁵. Associated Press, “U.S. Endorses U.N. Gay Rights Statement,” CBS News (online), at <http://www.cbsnews.com/stories/2009/03/18/national/main4873350.shtml>, accessed 14 October 2010.

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AmFAR noted that 71 percent of 128 countries surveyed in 2007 had no information on the percentage of gay and bisexual men contacted by HIV prevention groups; 44 percent had no data on these men at all. Because programming is supposed to be based on data, it only follows that with limited if any data on gay/bi men there are likewise limited or no prevention programs aimed at them. In Latin America, for example, less than 1 percent of total HIV spending goes toward programs targeting MSM.

Countries that criminalize homosexuality, with penalties ranging from prison sentences to death, have both high rates of HIV among gay and bisexual men (for example, 43 percent in Kenya, compared to the national 6.1 percent prevalence; 21.5 percent in Senegal, compared to 0.9 percent nationally) and few if any HIV prevention programs to target these men. No one can expect the men to come forward to seek care and support when doing so could mean risking imprisonment or worse simply for being gay or bisexual. Several donor countries have begun to take a stand against this deadly discrimination. The Netherlands, for example, adopted a policy requiring countries that accept Dutch HIV funding to end criminalization of homosexuality.¹¹³⁶

Back in the USA, too many seem to assume that the expensive, highly toxic chemotherapy enabling those who can access and benefit from it to live with HIV rather than die from AIDS is the end of the story. Unfortunately, they are as mistaken today as was blogger Andrew Sullivan in his 1996 proclamation in the

¹¹³⁶. American Foundation for AIDS Research, *MSM and the Road to Universal Access—How Far Have We Come?* (August 2008). At http://www.amfar.org/uploadedFiles/Articles/Articles/Around_The_World/MSM/ReportFailureToAddressHIVAmong-MSM.pdf, accessed 11 October 2010.

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New York Times Magazine of the end of AIDS, based on his own encouraging experience with then-new combination therapy.¹¹³⁷ In fact, as I interviewed advocates for this book, I was surprised by how often they mentioned Sullivan's article as an example of how one individual's opinion, when projected through a high-volume media megaphone, can muddle the public mind by creating the false impression that his own experience is typical for all HIV-positive people in the world. It is not.

The AIDS plague is not over. The facts speak for themselves: In the United States, 1.2 million are believed already to have HIV, a number that increases yearly with 56,300 new HIV infections in this country. All of us living with HIV in the U.S. represent only one twenty-eighth of the 33.4 million people infected with HIV worldwide. Just over five million total were receiving treatment by the end of 2009—a big improvement, but still only 36 percent of those considered to “need” HAART because of serious immune damage (it's important to remember that in the developed world, the trend is toward treating HIV infection as soon as possible after diagnosis), 2.7 million are newly infected and two million die from AIDS each year.¹¹³⁸

In an October/November 2010 commentary in *POZ* magazine, editor-in-chief Regan Hoffman and Tim Horn, president and editor-in-chief of AIDSmeds.com and a member of the national AIDS Treatment Activists Coalition, echoed Tony Fauci's assessment that it will be impossible to control the global AIDS pandemic—to end the plague—without some sort of cure. “The cost of providing antiretrovirals (ARVs) indefinitely to all people

¹¹³⁷. Andrew Sullivan, “When AIDS Ends,” *New York Times Magazine* (10 November 1996).

¹¹³⁸. UNAIDS, *UNAIDS Report on the Global AIDS Epidemic 2010*.

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globally who will need drugs to survive is staggering,” they said. “It’s estimated to be in the tens of trillions of dollars, not accounting for inflation, an ever-growing caseload, and future drug prices.” They listed some of the many reasons lifelong treatment isn’t the optimal solution for dealing with HIV: It is prohibitively expensive (the lifetime cost of medication alone can exceed \$600,000 per person). Medication can’t eliminate stigma, discrimination, and criminalization. It doesn’t relieve fear of rejection or of transmission. And it doesn’t guarantee against sickness and death from side effects related to the treatment itself. Moreover, they said, “If we can’t achieve universal access in the United States, our prospects for achieving it globally seem dim.”

Hoffman and Horn noted that the National Institutes of Health have spent *a total of only \$45 billion on all forms of AIDS research in the twenty-eight years since the institutes first supported it, an average of less than \$2 billion a year* [my emphasis]. Yet in 2009 alone, the US spent \$20 billion on domestic and global HIV prevention and treatment. In fact, said the writers, research, advocacy, and funding for HIV/AIDS since the late nineties—that is, since HAART came into use—have focused mainly on prevention and treatment. “And yet,” they wrote, “it has become clear that we can neither treat nor prevent our way out of the pandemic. The ethical, logistical, sociological, and financial barriers to trying to end AIDS with pills and awareness campaigns are proving too great.” The only realistic solution? Find a cure. Doing so will require governments to combine efforts and resources. Biotech and pharmaceutical industries should realize that investing in a cure for HIV will provide a healthy profit. The NIAID’s new five-year, \$8.5 million per year Martin Delaney HIV cure research initiative is a good start, but only a start. *POZ* founder Sean Strub said, “If Pharma [the pharmaceutical industry], the public health establishment, and AIDS service organizations lobbied for funding for cure re-

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search the way they lobby (directly and indirectly) for ‘routinizing’ testing, PrEP [pre-exposure prophylaxis], ‘Test and Treat,’ etc., this would be \$8.5 billion rather than \$8.5 million.”

NIAID AIDS director Carl Dieffenbach announced in August 2010 that AIDS cure research would be one of the top four NIH priorities in 2011. “It is up to us to keep the heat on that promise,” said Hoffman and Horn. Or, as Philadelphia-based AIDS Policy Project executive director Kate Krauss, put it, “We have a chance to dismantle this pandemic. What we do now as activists could determine whether the AIDS pandemic lasts another seven years—or thirty—and who will outlive it.” Krauss’s group has called for the NIH to increase AIDS cure research funding to \$240 million in 2011 and \$600 million a year within five years.¹¹³⁹

Of course even a cure would be useless for those who don’t know they are infected. As NIAID director Tony Fauci said, testing and treating those who are infected as soon as possible is the first, necessary step—for their own health, to lower their risk of infecting others, and to minimize the amount of latent virus after treatment to maximize their benefit from a potential cure.¹¹⁴⁰

In an effort to reduce the large number of people who don’t learn they have HIV until their infection has reached an advanced stage, New York State in September 2010 amended its public health law to require that every hospital, emergency de-

¹¹³⁹. Regan Hoffman with Tim Horn, “From Mice Into Men,” *POZ* (October/November 2010), at http://www.poz.com/articles/Mice_Men_HIV_2536_19163.shtml, accessed 13 October 2010.

¹¹⁴⁰. Fauci interview.

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partment, doctor's office, and outpatient clinic offer HIV testing to anyone between age thirteen and sixty-four receiving treatment for a non-life-threatening condition. The new law also requires providers to link those who test positive to care and treatment if they consent.¹¹⁴¹ The following month, Washington, DC, began to offer free HIV testing at the District's motor vehicle office in the largely Black Ward 7 in Southeast DC. Rapid oral test results would be available in twenty minutes and those tested would even receive fifteen dollars toward the cost of their DMV services.¹¹⁴² Largely through such initiatives, aimed at increasing access to HIV testing and thereby identifying those with the virus and making sure they had access to medical care, the District increased its testing from forty-two thousand tests in 2006 to one hundred ten thousand in 2010.¹¹⁴³

Once people are tested, though, the question remains as to when, exactly, those who test positive should begin treatment. The answer is unclear and involves weighing the plusses (reduced risk of HIV-induced health problems and infectiousness) and minuses (including possibly discomforting and damaging side-effects and the cost) of the medications. Treatment Action Group director Mark Harrington told me, "The biggest question in HIV treatment is when to start ART [antiretroviral thera-

¹¹⁴¹. United Press International, "HIV Test a Routine Part of NYC Healthcare" (1 September 2010), at http://www.upi.com/Health_News/2010/09/01/HIV-test-a-routine-part-of-NYC-healthcare/UPI-53751283389940/, accessed 14 October 2010.

¹¹⁴². Nikita Stewart, "DC Bringing Free HIV Testing to the Crowd at Motor Vehicles," *Washington Post* (1 October 2010), B1.

¹¹⁴³. District of Columbia Department of Health, *Annual Report 2010*. Washington, DC: HIV/AIDS, STD and TB Administration, 2011.

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py].” He said the NIAID-supported START (Strategic Timing of Antiretroviral Treatment) trial,¹¹⁴⁴ involving four thousand participants at ninety sites in thirty countries, will provide the clearest answers yet on the best time to start a newly diagnosed person on medication.¹¹⁴⁵

Meanwhile, San Francisco’s public health department in early 2010 charted its own controversial new course of recommending, and providing, treatment to those newly diagnosed with HIV regardless of the state of their immune system. The policy had equally prominent critics and supporters. “It’s just too risky,” said Dr. Jay Levy, the University of California–San Francisco virologist who was among the first to identify the cause of AIDS. The new drugs may be less toxic, Levy said, but no one knows the effects of taking them for decades. On the other hand, Dr. Fauci told the *New York Times*, “The field is moving, inexorably, to earlier and earlier therapy.” He called San Francisco’s decision “an important step in that direction.”¹¹⁴⁶

Although the U.S. has made major strides toward reducing the stigma associated with HIV—the biggest single step has been to loosen the association of HIV with disfiguring illness

¹¹⁴⁴. <http://clinicaltrials.gov/ct2/show/NCT00867048>, accessed 14 October 2010.

¹¹⁴⁵. Harrington interview.

¹¹⁴⁶. Sabin Russell, “City Endorses New Policy for Treatment of HIV,” *New York Times* (3 April 2010), at http://www.nytimes.com/2010/04/04/us/04sftreatment.html?_r=1&scp=1&sq=San%20Francisco%20early%20HIV%20treatment&st=cse, accessed 14 October 2010; Liz Highleyman, “SF Health Officials Advise Early Treatment for People with HIV,” *Bay Area Reporter* (15 April 2010), 1.

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and death—people with HIV, gay and not, still face illegal discrimination and totally legal criminalization on a regular basis. An eye-opening 2009 survey by the Kaiser Family Foundation found that ignorance, misinformation, and prejudice against people with HIV persist even after three decades. One in five white Americans said a close friend or family member had died from AIDS or was living with HIV; four in ten African-Americans had the same experience. Eighty-three percent of those who knew someone with HIV said they would be comfortable working with an HIV-positive individual, compared with 65 percent of those who didn't know a person living with HIV. Half (51 percent) of adults said they would be uncomfortable having their food prepared by an HIV-positive person. Thirty-five percent of parents said they'd be uncomfortable if their child had an HIV-positive teacher. Kaiser said these attitudes could be linked to the fact that levels of knowledge about HIV transmission have not improved since 1987.¹¹⁴⁷

Not surprisingly, discrimination, and criminalization continue apace with the ongoing ignorance. This means vigilance must continue on the legal front, as it must do at the frontiers of behavioral and medical research aimed at preventing and curing HIV. Bebe Anderson, director of New York City-based Lambda Legal's HIV Project at the time of our 2010 interview, said most discrimination cases filed on behalf of people with HIV could be traced to an employer's lack of factual knowledge. "Time after time," said Anderson, "these cases arise when an employer doesn't understand how HIV is transmitted." Anderson said it's a "constant struggle, a battle, still" to fight these cases. She emphasized that the cases Lambda Legal sees are "just a slice of what's going on." When cases reach the courts, Anderson and other lawyers' job often is to educate the judges and juries

¹¹⁴⁷. Kaiser Family Foundation, *2009 Survey of Americans on HIV/AIDS: Summary of Findings on the Domestic Epidemic*.

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with the simple, widely available facts of how HIV is and is not transmitted.¹¹⁴⁸

Besides employment discrimination, Anderson said she was seeing more cases involving an HIV-positive individual charged with endangering the life of someone else, usually a former sexual partner. She referred to the hysteria in Michigan over an HIV-positive man charged with “bioterrorism” for biting a neighbor when the two were fighting one another. The judge ruled in 2010 that merely being HIV-positive was insufficient to accuse the man of unlawfully possessing a biological substance.¹¹⁴⁹ The year before, a thirty-four-year-old Iowa man was sentenced to twenty-five years in prison after pleading guilty to a charge of not disclosing his positive HIV status to another man before having sex with him.¹¹⁵⁰ The other man remained negative and was effectively exonerated of his own irresponsible behavior in having chosen to engage in unprotected sex with a stranger he’d met online. He was likewise absolved of his own suicidal naiveté in not considering that any man might affirmatively answer the question “Are you clean?” to get sex. Thirty years into

¹¹⁴⁸. Bebe J. Anderson, interview with author, New York City, 27 July 2010.

¹¹⁴⁹. Todd A. Heywood, “Activists, Advocates Applaud Dismissal of Bio-Terrorism Charges,” *The Michigan Messenger* (3 June 2010), at <http://michiganmessenger.com/38455/activists-advocates-applaud-dismissal-of-bio-terrorism-charges>, accessed 14 October 2010.

¹¹⁵⁰. Lynda Waddington, “HIV-Positive Man’s Prison Sentence Shines Light on Iowa Law,” *The Iowa Independent* (29 June 2009), at <http://iowaindependent.com/16351/hiv-positive-mans-prison-sentence-shines-light-on-iowa-law>, accessed 14 October 2010.

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the AIDS plague, there are still too many jaw-dropping examples of people with HIV suffering for others' fear, ignorance, and refusal to accept responsibility for their own actions.

HIV continues to spread, particularly among gay and bisexual men. We've had to figure out—as a community, but mostly as individuals—how to have sex in an epidemic. The message to “use a condom every time” has so many caveats attached—it “depends” on: your HIV status, your partner's, viral loads, most recent tests, who does what to whom—it's been long-since replaced by serosorting as a logical, if hardly foolproof, way to deal with the fact that positive and negative men interact sexually more than either is aware or wants to acknowledge.

Three decades on, it's been years since the gay political groups really pushed the federal government for prevention funding proportionate to our high percentage of those at risk for, or already living with, HIV in this country. The organizations once spoke out boldly against the federal government about the injustice of denying the need to fund prevention, services, and treatment for gay men dying from AIDS. Issues such as marriage are important, for some anyway, but not nearly as important as protecting the health and the very lives of many more gay men, irrespective of their skin color, marital or contributor status.

One of gay America's most important legacies from the AIDS epidemic is the model of holistic health care and social services provided by AIDS service organizations. Ken Mayer, medical research director at the Fenway Institute in Boston and a professor of medicine and community health at Brown University in Providence, Rhode Island, believes we'll continue to

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need organizations focused on HIV. But, he suggested, “there may be core principles that are generalizable.”¹¹⁵¹

Paul Jellinek was program vice president for the Robert Wood Johnson Foundation in the mid-eighties, when the philanthropy funded a multi-city program to replicate the AIDS services model in cities around the country. That model led to the 1990 Ryan White CARE Act, which provided hundreds of millions of dollars for AIDS care and support services. Jellinek told me the model has profoundly influenced thinking about long-term care for homebound people with other debilitating illness and the elderly. Given the model’s success, Jellinek said that AIDS service organizations and their advocates should think more broadly about their mission and role. “Instead of pushing just for the renewal of the Ryan White CARE Act,” he said, “these services they’re advocating don’t have to be an outlier, but move the whole health care system—not just for people with HIV, but for anybody with chronic illness.”¹¹⁵²

Washington, D.C.’s Food and Friends, a home-delivered meals program founded in 1988 by gay people to provide nutritionally appropriate food to homebound people with AIDS, is one example of an agency that has seen its future in serving people with other life-challenging illnesses besides HIV disease. Rather than dismantle the capacity they built over the years when better medical treatment meant fewer HIV-positive people needed their services, Food and Friends in 2000 chose

¹¹⁵¹. Mayer interview.

¹¹⁵². Paul Jellinek, telephone interview with author, 2 August 2010.

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to broaden their mission.¹¹⁵³ Executive director Craig Shniderman told me, “We knew we were driving by the homes of people with other illnesses, particularly cancer, whose nutritional needs were not different from people with AIDS. We see ourselves as health care providers, and health care providers generally take the view that every life is of equal value. That was the philosophical driver. If every life is precious, every life deserves our attention.”

Today, Shniderman told me, about half of Food and Friends’ three thousand clients are people with HIV; the rest are people with cancer and advanced stages of other illnesses. Forty-nine staff and eleven thousand volunteers assist the agency to maintain its high-quality services. And the expanded mission has brought in new donors whose contributions assist all clients. “We dramatically increased our funding base by expanding our mission,” said Shniderman. The Avon Foundation alone had already given more than \$2 million by the time we spoke in 2010. The funds were given to support a “Pink Ribbon” meal delivery service for breast cancer survivors, but Shniderman said they were also “helping underwrite the administrative costs for the entire organization.”

When he became director fifteen years earlier, Shniderman said three-quarters of the staff were gay compared to 30 to 40 percent today. The board of directors was gayer then. Today there is greater ethnic diversity. “One thing we now do, I think consciously,” said Shniderman, “is to be mindful of our connections to the gay and lesbian community.” He said it’s intentional the agency has a community outreach worker who is a gay

¹¹⁵³. John-Manuel Andriote, “The Spread of Aid; With Fewer People Debilitated by AIDS, Food Service Reaches Out to Others Who Are Sick and Needy,” *Washington Post* (23 May 2000), Health.

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African-American “because these are the diverse communities we want connection to.”

Shniderman described AIDS service organizations as “a gift from the gay community.” He explained, “We’ve come to understand this organization as a place to care for people with life-challenging illnesses. We’ve come to think of Food and Friends as an organization that is a meeting place for the community, and a place where the community can come to build and heal itself.”¹¹⁵⁴

I asked the chief executive officer of the world’s oldest AIDS service organization whether the agency still considers itself a ‘gay’ organization. Gay Men’s Health Crisis today serves some ten thousand clients a year, not all of them gay, white, or residents of Chelsea where the agency was located from its founding in 1982 until it moved to West Thirty-Third Street in early 2011. “We’re so gay!” said Marjorie Hill. “We have such deep roots in the gay community. We will always be proud of that.” She emphasized, however, that the agency is also more than just gay. “We have heterosexual men who come to Gay Men’s Health Crisis for services because we’re damned good at what we do. We have heterosexual women who come to GMHC, and have come to GMHC for many years for services, because we’re good at what we do.” Hill said GMHC’s gay heritage is bigger than the still-high percentage of its clients, staff, and donors who are gay men. “While we’re very committed to the gay community and to the visibility and social justice for LGBT people,” she said, “we’re committed to a better world.” And by contributing to a better world, both in terms of public health and social justice, she said, “We’re doing, I dare say, what our founding fathers wanted us to do.”

¹¹⁵⁴. Craig Shniderman, telephone interviews with author, 15 July 2010 and 20 August 2010.

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There was a great deal of controversy among New York activists swirling about at the time of our July 2010 interview concerning GMHC's planned move from its longtime home in the Tisch Building on West Twenty-Fourth Street to the new, larger, less expensive location in what is also the less accessible AP Building on Thirty-Third Street at Tenth Avenue. Some, including co-founder Larry Kramer, felt GMHC was losing its focus by leaving its original neighborhood, a slap in the face to the gay community that had birthed and sustained the agency for three decades. In response, Hill said, "The fulfillment of GMHC is not just so that Chelsea, if you will, is HIV-free. But the fulfillment of GMHC's true legacy is to reduce HIV infection in the world and the stigma that goes along with that." She added, "Most people really understand that as long as there are increasing numbers of people living with HIV there is going to be a need for GMHC and the GMHCs of the world."¹¹⁵⁵

Richard Schneider, Jr. is the founder and editor-in-chief of the *Gay & Lesbian Review Worldwide*. Known at the time of its 1994 beginning as the *Harvard Gay & Lesbian Review* (until Harvard got snippy about the name), the Boston-based journal is, in its own words, "something of a lingua franca for the thinking GLBT community nationwide...the place where the big debates about gay and lesbian culture and politics are often played out." The journal's readers are mainly people in their forties and older. I asked to interview Schneider because the *GLRW* would seem the natural forum for gay America's leading activists, artists, and intellectuals to examine the cultural, political, sexual, and social aspects of the AIDS plague that so profoundly shaped the lives of so many LGBT individuals, the gay civil rights movement, and modern world history.

¹¹⁵⁵. Marjorie J. Hill, interview with author, New York City, 27 July 2010.

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"I'm surprised I don't get more articles on the epidemic and on HIV in general," said Schneider. He also suggested there might be a reluctance to talk about it. "I think maybe there's a feeling that it's all been said. Then there's a feeling that, if you yourself are HIV-positive, you don't want to burden yourself or be a downer. People who are negative don't talk about it because it's not as immediately salient." Schneider said there seemed to be a "code of silence" among gay men in our own fifties age group—those who saw the worst of AIDS, at least in the U.S. He mentioned that his own father, a World War II veteran, never talked about his wartime experience. He believes his father suffered from post-traumatic stress disorder that led to his becoming an alcoholic. He suggested an even stronger suppressant might be holding back discussion of AIDS. "In American culture," he said, "everyone's got to be 'fine.' 'I'm fine, how are you?' There is a code or norm in our society about not wanting to talk about things that are unpleasant in general."¹¹⁵⁶

But our AIDS stories aren't only tales of sorrow. There are heroes to be celebrated, achievements to be marked. I wanted to know what the nation's most famous AIDS activist, gay America's loudest voice in the darkest years, thought about how to sustain the pride of the battles we won, honor our people's valor, and remember our fallen comrades. Larry Kramer said he is dismayed to find "more people who are ignorant of us than I find people who are interested in us." He cited two examples in his own experience. "A lot of gay people don't know who GMHC is," he said. "They certainly don't know who I am. I'm always amazed when anybody, gay or straight, knows who I am because that's just me." His conclusion? "We are very obliv-

¹¹⁵⁶. Richard Schneider, Jr., interview with author, Provincetown, Mass., 7 August 2010.

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ious about our history, period. We don't have a history we can claim.¹¹⁵⁷

Fortunately, gay people *do* have a history, even if we are still only beginning, and still sometimes only reluctantly, to claim it.

When the thirty-three men trapped underground for more than two months in a Chilean mine were rescued and brought safely to the surface in October 2010, I was struck by the parallels between the miners' experience and that of gay Americans who have lived through the AIDS years. The *New York Times* quoted New York University psychiatrist Charles Marmar as saying, "Except for a few miners who find reminders of the experience too painful, this group will become the most powerful social network these men have. They're bonded for life, like any group of cops or firefighters or war fighters who have shared a threat to life and united to survive it."¹¹⁵⁸ As NAPWA president Frank Oldham put it, "There is a tremendous bond there that enabled us—lesbians and gay men—to be such courageous caregivers during the AIDS epidemic when our friends were going to funerals and services, when hospitals wouldn't touch our friends and lovers. It's almost like those of us who survived are being released from the concentration camps."¹¹⁵⁹

¹¹⁵⁷. Kramer interview.

¹¹⁵⁸. Benedict Carey, "Fame to Affect Adjustments for Miners," *New York Times* (12 October 2010), at http://www.nytimes.com/2010/10/13/world/americas/13psychology.html?_r=1&hp, accessed 15 October 2010.

¹¹⁵⁹. Oldham interview (4 May 2010).

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Keeping alive the memory of pride and pain, what we learned of our own resilience and strength, is a challenge our community organizations continue to face—and must meet. It's also a challenge for each one of us who lived through the first three decades of AIDS. Claiming the power, pride, and perseverance with which gay America responded to the AIDS plague redefines what "gay" means to include brave, courageous, and loyal—the virtues passed down the ages from our spiritual forefathers, the same-sex-loving warriors of the Sacred Band of Thebes themselves, the original army of lovers.

Darlene Nipper, the deputy director of the National Gay and Lesbian Task Force, called it "the heroic and valued legacy," the heritage of love and defiant life in the face of hatred and death that gay Americans have demonstrated. Nipper said organizations like the task force can help preserve and pass on our stories. "We better tell folks what's happened in our community," she said, "over and over and over again, both the horror stories as well as the incredible impact we had."¹¹⁶⁰

At the L.A. Gay and Lesbian Center, Lorri Jean said a "huge" piece of a new program being developed to groom new LGBT leaders is "educating them about our history because they're the ones who are going to have to pick up the ball and carry it the rest of the way."¹¹⁶¹ She listed books, like this one, and documentary films as some of the ways to preserve our history. To mark the thirtieth anniversary of AIDS in 2011, Sean Strub told me in 2010 a number of films and documentaries were in the works. "As the pain in our community has

¹¹⁶⁰. Nipper interview.

¹¹⁶¹. Jean interview.

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lessened,” he said, “the need to tell our stories is greater.”¹¹⁶² Recent films have included David Weissman and Bill Weber’s *We Were Here: Voices from the AIDS Years in San Francisco* (2010), and *Last Address* (2009), an 8:36-minute short film by Ira Sachs that simply shows the facades of buildings throughout New York City that were the final homes of artists who died from AIDS between 1983 and 2007.

Other than the brief, Tony Award-winning Broadway revival of Larry Kramer’s *The Normal Heart* in the spring of 2011, and an earlier short-run revival of Tony Kushner’s now-mythic and widely performed *Angels in America*—the theater, which had so powerfully dramatized gay people’s anger and pain during the angry, painful years, seems to have taken its cues from the national gay political organizations, judging by the degree to which it has “moved on” from AIDS to focus mainly on love stories.

Patrick Healy reported in the *New York Times* in early 2010 that cultural depictions of the AIDS crisis for gay men started to ebb in the mid-1990s, just as effective HIV treatment began to dramatically slow the death rate and, of course, point up the disparity between the experience of white middle-class gay men and that of lower-income gay men of color. “In the 1980s and early nineties,” wrote Healy, “the stories of gay men in plays like *As Is*, *The Normal Heart*, *Jeffrey*, and *Love! Valour! Compassion!* often rendered loving or lonely characters against a backdrop of activism or ideological criticism of the seeming indifference of government and society to fighting AIDS or treating gay Americans as equal citizens.” In contrast, said Healy, new shows “are at their heart about remarkably unremarkable love stories—romantic or platonic—among gay people.” He said the shift from explicit political statements to “subtler story-

¹¹⁶². Strub interview.

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telling” reflected the debate in gay political circles about whether to continue fighting at the ballot box and in the courts for gay rights immediately or instead to take a longer view that involves building alliances and giving time for more Americans to come around on issues like gay marriage.”¹¹⁶³

Novelist Fenton Johnson knows about using stories to record and sort out difficult chapters of history, particularly personal history. “From the first,” he told me in 2010, “I’ve seen HIV as an issue that affects everyone equally, regardless of sexuality.” This is why he “steadfastly resisted” calling his 1996 book *Geography of the Heart* an “AIDS memoir.” Instead he insists the true personal story of being an HIV-negative man caring for his positive lover who died from AIDS is “a memoir whose central characters were caught up in the epidemic, yes, but that doesn’t make it ‘an AIDS memoir.’” AIDS, said Johnson, “challenged us to be the biggest people we could be, and we rose to the challenge.” Now, he said, the questions are how to make the challenge real for those who didn’t live through them, how to draw from the power of the ‘army of lovers’ battling the two-headed enemy, HIV and homophobia. In the end, chronicling our stories and passing on what we know comes down to the very thing Harvey Milk was so adamant about in his vision of gay liberation: hope. Said Johnson, “I think one has to figure out a way of offering hope, because there is no future in despair.”¹¹⁶⁴

¹¹⁶³. Patrick Healy, “New Gay Theater Has More Love Than Politics,” *New York Times* (22 February 2010), at <http://www.ny-times.com/2010/02/23/theater/23gaytheater.html?scp=1&sq=New%20Gay%20Theater%20Has%20More%20Love%20Than%20Politics&st=cse>, accessed 19 October 2010.

¹¹⁶⁴. Fenton Johnson, telephone interview with author, 14 July 2010.

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There it is, then, the key to good health and effective HIV prevention and treatment for gay men: hope. Our future, our health itself, lies in rediscovering, and embracing, the simple creed of the slain leader who recognized the enormity of his own symbolic role as America's first openly gay elected leader: You have to give the people hope. Hopeful people are more likely to respect and protect themselves and their partners, and to access and adhere to medical treatment that will keep them well and reduce their risk to others. An ongoing challenge in the AIDS plague has been knowing how to inspire life-preserving hope in gay men who are told, beginning in childhood, that we are sick, sinful, criminal, second-class, and destined to premature death at the hands of a basher infected with hate or a lover infected with HIV.

"We need to do everything we can to protect our youth," said Ron Stall, after talking about what it would take to raise healthy, confident young gay men with a strong chance of avoiding HIV. He said that one of the most effective HIV prevention interventions would be for older gay men to serve as mentors for younger guys. "We need to find ways for gay men to play roles as models working with young men," he said. Stall dismissed as "bullshit" the stereotype of older men preying on helpless youths. "Most gay men do not want to have sex with a sixteen-year-old," he told me. "But a lot of gay men would like to make sure that a kid will get through his adolescence without being roughed up the way they were." For kids who have run away from home, or have been kicked out—the so-called "throwaway" kids—Stall said older gay men could provide a safe refuge. "There are bound to be older gay men out there who would be willing to 'play dad' to help a kid make it," he said.

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Still another way to address the syndemics of substance abuse, depression, violence, and the like that undermine so many gay men's health, would be to teach parents how to help their gay kids. Said Stall, "The proper response when John comes home and says 'Mom, I'm gay' is not to throw him out of the house." As Caitlin Ryan's research found, supportive parents can literally mean the difference between life and death. Stall added, "Getting beaten up on a playground may turn out not to be as long-lasting if boys can come home and have a parent who says 'Those kids are assholes. I love you just the way you are.'"¹¹⁶⁵

Columbia University psychiatrist Robert Kertzner said gay men, like other people, revise our identities in our forties and fifties; it's a natural part of human development. But he said AIDS seems to have caused many to revise their identities away from the gay community—rather than to remain engaged as its elders, story-bearers, and wise men. Kertzner also said older gay men have roles to play as mentors. Mentoring, of course, involves sharing knowledge and wisdom, what we know about life and love. It also means opening hearts that may have been shut off long ago to block out the pain around us. For many of us, AIDS has been both battleground and classroom. Of course mentoring also requires interested mentees. Said Kertzner, "Younger people who have the perceptiveness to understand the value of sitting with older people and reflecting on what the older folks' experience means in their young lives, there aren't too many." A problem, he said, "is younger people dismiss older people as being an artifact of an earlier time."¹¹⁶⁶

¹¹⁶⁵. Stall interview.

¹¹⁶⁶. Robert Kertzner, MD, telephone interview with author, 19 July 2010.

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Fortunately, most mentor relationships don't depend on sexual attraction, a factor that often seems to stand in the way of non-romantic relationships between generations of gay men.

Mentor relationships have altered the course of lives. Some have even led to the salvation of many other lives. One such relationship was that of Reggie Williams and Albert D. Cunningham III. Both men were going about their respective lives, working in their jobs on opposite coasts, when AIDS brought them together and changed them and the world forever. Williams in 1988 formed the first national organization dedicated to preventing the spread of HIV among gay men of color. Cunningham joined him and a small but dedicated staff in San Francisco, lending his years of communications experience to serve as the media director for the National Task Force on AIDS Prevention. When Williams died, in 1999, Cunningham wrote his obituary, paying tribute to the man who had been a giant in his own life and in his outsized role as a champion of gay men of color.

"Reggie was a supervisor of radiology at Cedars Sinai Hospital in LA," Cunningham told me. "I was a public information officer for the District of Columbia. I didn't envision HIV work as a career path, but rather as a temporary assignment." Cunningham said working on HIV issues today is different, and not only because of the improvements in medical treatment. "I work with many committed people, especially younger people who don't know a world without HIV and are starting their careers in HIV-related activities," said Cunningham. "Unfortunately, many of them don't have a Reggie Williams, an Essex Hemphill, or a Marlon Riggs in their lives as peers and mentors, as I did. I keep Reggie's photo on my desk at work as a constant reminder of his focus, which was always people. He was never too busy or important to encourage, educate, empathize."

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Like Arnie Kantrowitz's gold lambda ring from Jim Owles, the photos of his dear departed friends Owles and Vito Russo still displayed in his living room, Cunningham said, "I keep my *Tongues Untied* poster in a prominent place on my wall, with its inscription fading, yet etched in my mind: Marlon's challenge to 'Always be true'; Essex's reminder to 'Continue taking care of those blessings and keep your faith.'" Recalling his personal mentors and describing his own role today—mentoring younger people, keeping alive the legacy of the giants who have walked among us and the hope they kept alive through the darkest years—Cunningham said, "I feel a 'cloud of witness' around me, scores of friends, lovers, comrades-in-arms, whose lives have enriched mine, and continue to do so, long after their departure from this plane."

Cunningham never expected anything after the civil rights movement of the 1960s to impact his life as significantly as AIDS has done. "Now," he said, "it would seem those developmental experiences were but a prologue, an internship that provided a framework for the past twenty-five years' struggle in the face of HIV/AIDS. The values and experiences of Community in those formative years have sustained and propelled me through the turbulence, tragedy, and personal devastation of this plague, which is far from over."¹¹⁶⁷

¹¹⁶⁷. Albert D. Cunningham III, e-mail to author, 7 August 2010.

INDEX FOR THE 2011 SECOND EDITION

Although it isn't possible to create an index in an ebook, this is the index for the paperback 2011 second edition of Victory Deferred. It offers a valuable resource by providing the names of individuals and organizations named in the book, as well as important dates, events, reports, etc.

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